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ABSTRACT

This study examined barriers to utilizing services for children, birth to age 3, through in-depth individual and group interviews with 70 parents and direct service personnel of provider agencies in seven Washington counties. Part 1 of this report offers examples and discussion of the difficulties parents have accessing services and how localities try to improve their services. Part 2 explores the specific experiences of parents from special populations, including rural or urban locations, poor, Hispanic Migrant, American Indian, or military. Among findings were the following: (1) the presence of a moderately to severely disabled infant or toddler challenges every aspect of a family's life; (2) the array of early intervention services is perceived as a patchwork of pieces or as a maze in which it is possible to "fall between the cracks"; (3) accessibility is a more major issue than availability of services; (4) Interim Family Resources Coordinators are seen as useful intermediaries; (5) parents need the support of other similar parents; (6) existing services are not adequately family-centered; (7) local efforts at better coordination of services cannot overcome basic system problems; and (8) parents fear health care reform, at both the state and federal levels. An appendix provides additional information on the study's methodology. (CR)

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Exploratory Study of Barriers to Birth to Three Services:

Children with Disabilities and Special Health Care Needs in Washington State Public Programs

Washington State
Department of
Social and Health Services
Planning, Research and Development
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Exploratory Study of Barriers in Birth to Three Services:

Children with Disabilities and Special Health Care Needs in Washington State Public Programs

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When ordering, please refer to Report 7.78

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Executive Summary

Exploratory Study of Barriers to Birth to Three Services

Thomas Lonner, Ph. D
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Parents of Disabled Children

The presence of a moderately to severely disabled infant or toddler challenges every aspect of a family's life—the parental relationship, the welfare of siblings, the ability to earn a living and pay bills, the ability to pursue careers and other ambitions, the physical capacity of the family's dwelling, relationships with extended family members and friends, and parental physical and emotional well-being.

Services System or a Patchwork

The array of early intervention services, marked by scarcity, is also seen as a patchwork of pieces; it is experienced by most parents as a maze rather than a system. Both parents and agency personnel report that it is easily possible to get "lost in the shuffle" and "fall between the cracks" among programs and never get "plugged in."

Gates to Service

While there are shortages of providers, money, and other resources in early intervention services in all counties, the major issue in services does not appear to be "availability" but "accessibility". The needed services, however scarce, are available, but there are multiple and complex gates to the services which are either shut or difficult to pass.

Parents Need IFRCs to Pass Gates

Interim Family Resources Coordinators (IFRCs) occupy a space somewhere between "parents" and "agency". As parents of children with disabling conditions, they provide some of the validation, information, support, planning, and referral to services and other families that parents seem to need.

Parents Need Other Parents

Most parents cannot survive or succeed in isolation but need the support of other **similar** parents. The "survivors" hang together, mutually supporting each other, rather than drawing on the larger resources of "normal" families in the community. They form a sub-culture, with powerful bonds formed from the reactions to and manner of surviving their situations.

Do the Early Intervention Services Serve the Family?

A true family-centered approach to care appears to be the least developed aspect of care in the service system (for example, lack of respite care). Without this additional investment in the families who provide the skilled care to the infants and toddlers, the investment in medical therapy alone may not be sufficient to meet either service agency or family goals.

Local efforts at Better Coodination

While local innovations tend to strengthen certain aspects of service, they do not overcome basic system problems, such as categorical funding, low reimbursement rates, lack of sufficient numbers of providers, and lack of respite care.

Parents Fear Health Care Reform

Parents see health care reform, at both the state and federal levels, as providing

- a more medical than family-centered approach to disabilities,
- fewer options,
- fewer and tougher gatekeepers, and
- an overemphasis on cost reduction.

The qualitative findings emerge from one to four hour in-depth, structured, open-ended interviews conducted April-May 1994 in seven counties among seventy respondents: parents, resources coordinators, private and public service providers.

Study funded by ***DSHS Birth to Six State Planning Project,*** *conducted by the* ***Office of Research and Data Analysis, DSHS: Report 7.78, September1994.***

Families' Different Experiences with Early Intervention Services

The experiences of families with local early intervention services were significantly differentiated by geographic location, by poverty, and by being members of special populations. Location, poverty, ethnicity, and unique services systems combine in different ways to make the experience of some families very different from others.

Rural-Urban

Rural care is viewed by local informants as having the advantage of smaller numbers of children, highly visible in smaller communities with families informally referred to various services by a more personal interagency network. It is generally agreed that the weaknesses of rural care are the lack of specialist providers, lower skill levels and transportation problems.

Conversely, urban care is seen as providing more plentiful and varied services, but with more complex, formal relations among agencies and providers. Because of these complexities children may get lost and family needs may be overlooked.

Poverty

Characteristics often associated with poverty include:

- geographic and seasonal mobility that impedes agency contacts, service information, and parent-to-parent supports that such families need; and
- different priorities and different language that contribute to families' distrust of agencies and providers' bias against poor families.

Hispanic Migrant, American Indian and Military Families

Cultural differences and unique services dedicated to special populations (migrant councils, Indian health services and military health care policies) complicate attempts at building common interagency networks. The consequences tend to be mutual suspicion, rejection and underservice.

The exception is migrant councils, which hire Hispanic paraprofessional advocates who specialize in screening, diagnosis, and referral and help maximize community-agency efficiency and coordination in delivery of services to Hispanic parents.

CAUTIONARY NOTE

Caution needs to be used in generalizing these and other findings of this exploratory study. The strength of the analytic method used (Glaser and Strauss' The Discovery of Grounded Theory) lies in the emergence of clearly identifiable common patterns of findings from the different perspectives of key community informants and parents of children with developmental delays in purposfully chosen localities. However, statewide prevalences of these common patterns cannot be determined. Nor can we assess statewide magnitude of parental needs and barriers to service we identified. Further studies with statistically generalizable random samples are needed to answer questions of prevalence and magnitude.

Study Purpose and Methods

What is the Purpose of this Study?

The purpose of this study was to examine, on behalf of the Birth to Six State Planning Project and the State Interagency Coordinating Council, barriers to Birth to Three services in four Washington counties. Actually seven counties were studied since service areas included some counties close to the original four counties chosen for study.

The report summarizes some of the major findings of this exploratory study of barriers as seen and explained by parents and direct service personnel of provider agencies in these counties.

What Methods Were Used?

In-depth individual and group interviews were conducted with over 70 key informants in seven counties about their experiences with and reflections on barriers to services in their locations. There was remarkable accord among the perceptions of parents and service personnel (agency supervisors, case managers, public health nurses, teachers, interim family resources coordinators) both within counties and across counties. The interviews revealed a number of conditions and processes which, together, explain the gap experienced between parents' needs and the provision of local services.

The original focus was on four counties chosen to represent diversity in geographical location, in ethnic/racial composition and degree of integration of services. Additional interviews were conducted in three other counties contiguous to the original four. The sample of service personnel was aimed at representing all major providers in the local service area. The sample of parents was a "snow ball" sample: each parent or group of parents interviewed introduced us to other parents, starting with parents identified by service providers or coordinators.

The exploratory study assumed that parents and service personnel live under real and specifiable family, community, and agency conditions in their counties; that their values and culture guide them in how they perceive, understand, and interpret these conditions; and that their subsequent words and actions derive from these views of themselves.

What emerged were recurrent patterns in the experiences and explanations among parents and providers in these counties. However, it is not possible to generalize findings from these key informants to all parents, agency personnel, agencies, programs, counties, providers, or issues. Generalizability will require a different form of research. A full discussion of the method and limitations of the exploratory methods used appears as Appendix 1 of this report.

The interviews provided a wealth of systematic information about how parents seek and discover information, personal support, and care for their child. This wealth, a more detailed discussion of topics in this report, and related issues appear in the project's lengthy source document, "Birth to Three Early Intervention Study: Enrollment of Washington Children with Disabilities and Special Health Care Needs in Washington State Public Programs," available upon request from the Office of Research and Data Analysis. The following excerpts from a single transcribed interview of a parent clearly reveal this wealth.

One Family's Experience

One mother of a multiple-handicapped dying child reported:*

We had a hideous experience getting started in the system. We got lost; we didn't get picked up until my daughter was five months old.

The parents, who had other children, noticed that something was wrong immediately after her birth.

Diagnosis

The hospital said that she was fine, that all babies spit up. They were very dismissive of us and accused us of being paranoid. We made the rounds of the local pediatricians and family doctors for the first two or three weeks and got no answers either. By chance, a pediatric resident from [major out-of-county hospital] was here and took a look at her. Perhaps the biggest thing he did was listen to me. Based on what I told him, he called the hospital to set up tests.

All the people in the hospital listened to me and documented what I said in the records — her manner of breathing, the look in her eyes. They recognized the condition from the information I had. Everything was treated as important information and formed the basis of ongoing exams.

She responded to their care, I brought her home, and two days later she was back in the local hospital. They failed fourteen attempts to start an I.V. They were going to put her in the operating room for a cut down I.V. but a nurse took us aside and told us that we had the right to take her back to [major out-of-county hospital]. She was there for almost three months and I stayed with her the whole time, unless my husband and kids came over to spell me.

Finances

Our finances went from good to awful by that time. We were writing bad checks, borrowing money everywhere we could; my home business which I had for eight years went right out the window. We had excellent insurance from my husband's work. Once the out-of-pocket costs exceeded $1200, which happened at her birth, technically everything else was covered. But my loss of income and his loss of income was severe.

Her primary physician over there was a pulmonary physician; she provided diagnostic and treatment guidelines to a local pediatrician. We struggled for three months with her recurring bouts of pneumonia, totally on our own with no family here other than our own kids.

Supports

Our friends here were pretty intimidated by her problems, tube feeding and awake apnea spells, but they took our other kids out for pizza and things like that. We had no agency supports, other than our weight checks at the pediatrician's office, and in and out of there for infections. He didn't refer us to anyone else, but would say things like, 'You've got to get more sleep,' because I was a walking zombie by that time. Good suggestion, but no way to do it.

* *Shaded text indicates direct quotation.*

Information Again, by chance, we ran into the parents of a child who had been in the room next to ours and they asked, 'So, whatever happened to your baby?' We told them and then again by chance, bless their heart, they knew the system, they asked, 'So, did you get SSI?' I asked, 'What's SSI?'* 'Did you get CSHCN support?' 'What's CSHCN?' ** They started rattling all this stuff off. 'What are you doing? Who's helping you at home?' I said, 'Nobody, who helps people like us?' They gave me the name of a health advocate.

Advocate I called her. By that time I was a basket case and bawling. She told me to hang up, she was coming right over. That opened up the whole system That was the main gate, because she put all of the wheels in motion, then all of other agencies started calling me. They all prefaced it by saying, 'We don't want to overwhelm you right now. We are all in crisis here because we want to help you but we don't know where you have been, how this could have happened, and we all want to be there to help.' They immediately recognized that we had been lost for months. They were shocked, 'How could a tube-fed baby be sent home in this community and we not know about it?'

Referral They identified the biggest culprit to be the local pediatric clinic, that they never made a referral to local birth to three services, even though they knew she had chronic health problems and would be developmentally delayed, and they knew that the family was falling apart at the seams. They were surprised that [major out-of-county hospital] didn't make a referral, either; since that time, the pulmonary unit social worker formally apologized to us, since they could have started the SSI application while she was still in the hospital. No one even suggested it to us. It would have helped us immensely, since we lost eight months of benefits.

Application The health care advocate came to the house and did most of the SSI paperwork or walked me through every bit of it, helped me prioritize stuff in there, and did all of the photocopying and mailing for me. I was totally home-bound at the time.

Supports The public health nurse helped me with the CSHCN qualifying paperwork by phone and mail, since she was on leave from work. We had hundreds of dollars of 20% co-pay due on prescriptions and the public health nurse assisted us in paying for our deductible and cover some front-end co-pay costs. She also ran interference on one of our hospital bills that the hospital had turned over for collections, knowing that our baby was on CSHCN and we weren't to be billed for it. During all of this period, I kept notifying our credit bureau of what was happening and why everything was so late. That's why we were so upset at the collections thing. The public health nurse called the hospital and had them reverse it. She was fantastic.

Resource Coordinators Four birth to three people came over, for three different visits, and tested my daughter. By that time, we were so lost, adrift, traumatized, and so far under that having all of these new people were lifesavers to us, knights in shining armor. Other people think that is very invasive but we thought, 'Thank God.' They said, 'Yes, something is the matter and we are going to help.' They supported my daughter, they supported us, tender and caring, and they supported our kids. They zeroed in on the kids. They didn't just do the tests and leave.

* *Supplemental Security Income, DSHS income assistance program.*

** *Children with Special Health Care Needs, Department of Health program.*

The DDD* case worker got us qualified and she became our case manager. I am not sure how it happened to be her, but there she was. I think I filled out a form that requested it.

The birth to three program put a big meeting together and asked us, 'What do you want? What do you need?' I said, 'I don't know, I need help. I'll take anything you can offer.' That's when we got a case manager. I wasn't in any condition to be my own case manager.

Getting into Services

By that time, I had completed all of the forms to qualify for services. DDD services had a waiting period of five months, since funds were frozen. The DDD case manager pushes the limits to get the kids in most need high up on the list. A window opened and two kids got in, one of whom was my daughter. We got respite and personal care, a baby monitor because she had awake apneas, a cellular phone for when I'm away from her, different equipment, a play pen, family activities for the other kids, gas and ferry vouchers. The community donated a family pool pass for the swimming pool so we can take the kids out.

New Diagnosis

At eight months, I was telling the pediatrician that she was still not sitting up or rolling over and they kept saying this was due to chronic hospitalization and these things were to be expected. I took her back to [major out-of-county hospital] and she was diagnosed with a second condition, a brain disorder predictive of early death, and that created another major crisis for us. We turned to each other, to our friends, and to the nurse from the pulmonary clinic who had become our friend; as a matter of fact, she came to our care conference after the new diagnosis. Given the new diagnosis, we transitioned from pulmonary care to neuro-developmental for primary medical case management. Both teams really worked together to make the transition as smooth as possible.

Supports

When we got back, all of our local supports found out and helped us. Everyone got copies of everything we all had to know about the new condition. We had been planning to move to Montana, closer to our families; we thought we could continue with the tube-feeding anywhere. With seizures and other life-threatening stuff, we changed these plans instantly. The communities where we looked had nothing like the range of birth to three stuff we have here, they were barely getting started with Headstart. We saw quickly how blessed we were here. The support system kept us here, even though we have no family here. This is where we were going to get our needs met.

The entire support system, the entire community, helped to support the other kids. There was an article about us in the local paper, the birth to three program people, the other families in the program, all were supportive. Here, the only thing that is lacking is a parent support group, to know that we're not alone when it's three o'clock in the morning and we have not slept for three nights, and the alarm goes off in her room and my husband and I start fighting over whose turn it is. I want to know whether we are not the only people in the world going through that. That's my greatest need, to know that we are doing the best we can in a very difficult situation.

* *Developmental Disabilities Division of DSHS*

Parent Support

Last year, birth to three had some funds for a parent support group, with some invited speakers, and some of us came, including more and more of the dads, and a lot of stuff came out and was shared. Then the school year ended and the funding stopped. When the school year started, there were still no funds. We started champing at the bit, because even in the informal support group there were lots of parents of teenagers and that was not where we were at. We're into medical crises, 'diapers and how to get them', and getting SSI, while the others are beyond medical crises and into wheelchairs. Once you're over six and into the school system, you're in a whole other spectrum. You're not advocating for the same kinds of things because you're not there yet.

So, two of us who had our kids at the same time at [major out-of-county hospital] and whose kids have medical conditions and crises which keep us homebound started having lunch together and talking about the needs. The state director of Parent-to-Parent offered to sponsor our parent support group. Funds would be lovely, but we can buy coffee at Costco and take turns making cookies and hosting meetings in our homes. The best thing about funds is that they cover the cost of childcare while we are meeting together, so that we can meet as adults. We're still trying to figure out how to get 10 different families to provide their own babysitting at the same time. I worry every day that I might lose my babysitter and my life, as I know it, might be over.

What is More Important

I can't tell what is more important — medical support, agency support, or parent-to-parent support. Depending on the day, I would give you a different answer. There are days I can't get up and get her ready for birth to three without knowing that the teachers will be there and tell me 'you're doing great, just keep doing it.' There are other days when I don't need that as much or at all. Because I do my part, they all, the entire agency support group, continue to support me.

If I failed my part, if I were a more helpless or needy person or if my husband weren't so strong and active...as a matter of fact, we see it all the time. I know some families who are too disabled to take advantage of what is right in front of them. Those are the ones I find the most difficult to help. One mom complained that she had difficulty in getting enough baby bottles and I offered to give her a case of them that we hadn't used because my baby was tube-fed and she whined, 'Oh, gee, I don't know how I'd get them.' I told her I would bring them over. 'Oh, I don't have any storage.' Here's a solution and they won't take it. I finally gave up, as a mom and as a parent-to-parent person. When the agencies finally give up, too, the child suffers.

Parents can only be intrusive up to a point with other parents. I go until they tell me not to go. It gets more complicated with the more rural families coming into town for parent support groups and other events for the families. I offer to bring them in my van and keep pushing until they tell me they simply don't want to come. I don't understand it. I can't understand how they can not take advantage of everything that's out there that could improve their child's life.

When we first started, the agencies told us to stop them if they were going too fast or doing too much. Some families have told the agencies to 'jump in the lake, I don't want to have anything to do with you.' With some children, we are all worried and concerned, agencies and other parents. But short of getting some authority in or encouraging parents to take advantage of parent-to-parent support, I don't know what else the agencies can do. We don't give up on them but we can't make it happen for them.

Parents are the greatest network for this information, absolutely. There are barriers within agencies which either keeps them from knowing things or sharing things they do know. Only some are very good at leaping over these boundaries. Agency people constantly pick my brain, 'What did you learn when you went over there?' The DDD caseworker even takes notes and sometimes calls me, 'Remember when you got money for that? Where did you get it? How did you get it? I've got another kid who needs that.' The prisoners know more about what is going on than the warden does.

There are also some families who play the system for all it's worth. Some of the most important things we learn about the system, we learn from families like that. They know the system, they learn how to play the victim, they find out how to access the help out there that way, how to play all of the alternatives in the system to get whatever is needed, to the point of abusing the situation. That is not my particular style, but I certainly use some of the information they have uncovered.

How typical is this experience?

This interview was typical of the parent interviews, in that each parent was able to describe the particular history of the need for, search for, and discovery of information and support. Given a very large number of variables which distinguish among parents, families, personal and community resources, cultures, and communities, the specific experience of each family is idiosyncratic, but certain basic elements are common across the families who were interviewed:

Parent/Family Needs

- the need for parents' perceptions to be validated by physicians and other supportive services
- support in the grieving process among parents, as their child's condition worsens or appears more clearly life-threatening
- the need for increased and more immediate parental awareness of public supports and services
- the need for increased parent to parent support and information sharing and the development of a culture among these parents
- the need for the parents to be strong in the face of great challenge
- the needs of siblings and other family members
- the need to tap community, as well as agency, supports

Technical Issues

- the effective hospitalization of the child at home, with parents providing the skilled 24 hour a day nursing care
- the lack of uniform and immediate referral from point of entry to the local network of support services
- the rapid decline of family income and increase in debt
- the need for considerable equipment support
- the presence of some hidden information vital to access services and resources
- the delay in receiving certain supports, such as respite.

What does it do to the family?

Care for the Family as Well as the Child

A true family-centered approach to care appears to be the least developed aspect of care for children with disabilities and special health care needs. Parents and agency line staff acknowledge that the pre-natal, post-partum, and following medical system services enable the children to survive very threatening conditions, but argue that the social service system does not sufficiently enable the family to survive as an intact family nor to succeed in being primary and effective care providers to their children.

Direct care providers tend to agree that most early intervention services and programs address the medical and developmental needs of the infant or toddler, but do not meet the array of the family support needs of the parents and siblings of the infant or toddler. They recognize that, without this additional investment in the families who provide the skilled care to the infants and toddlers, the investment in medical therapy alone may not be sufficient to meet either service agency or family goals.

Since agencies provide services during only a portion of the child's daily life, one of their objectives is to make their parents into skilled caregivers for their children and continue the treatment provided by professionals. But, as one provider noted,

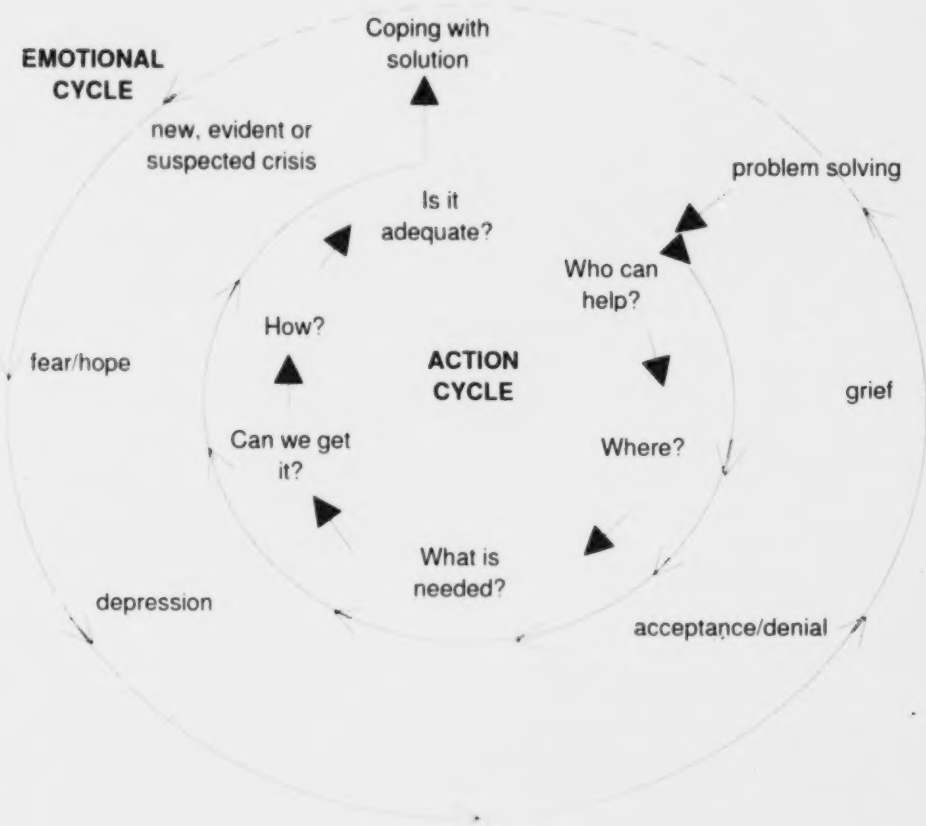
> family support seems to drop out of the picture first. Parents hardly ever get what **they** need, in order for the child to get what he needs, so that they can be the kind of parents that he needs to have.*

Help in Meeting Broad and Deep Challenges

Many families require a far broader and deeper array of services than is commonly recognized. The family interviews clearly revealed that the presence of a infant or toddler with a moderate to severe disability challenges practically every aspect of a family's life — the parental relationship, the welfare of siblings, the ability to earn a living and pay bills, the ability to pursue careers and other ambitions, the physical capacity of the family's dwelling, relationships with extended family members and friends, and parental physical and emotional well-being. Parents were not protected from the immediate and inevitable depression, grief, economic and housing losses, and other adjustments associated with the birth of a disabled or special health care needs child. These forces are reported to result in marital dissolution and/or relinquishment of the child to foster and institutional care.

* *All indented text is direct quotation from key informants*

Cycling of Parents' Experience with Crises: Emotional and Action Cycles



Note: Depicted above are some of the cycle components mentioned by parents in describing their experiences. We may not have identified all the components and their sequence. This chart tries to depict the interrelated and repetitive nature of the cycles.

Parents reported being tied to a day-to-day existence, because of the immediacy of the demands and, among some, the uncertainty of the future medical condition of the child. Some tend to block out and even deny what may happen to them and their child tomorrow and for the rest of their lives. As one mother said,

> Who has the energy? Will my son ever be able to write his name, use a toilet, get a job, get married, hold his own son, be independent of me? Yet my son could die tomorrow in an instant and none of this will ever happen. Or he could remain as dependent as an infant forever. If you think about this stuff, you start grieving all over again.

One basic condition facing some of these parents is a perpetual state of infancy for their children—fragility, dependency, uncertainty—resulting in great demands on parental time, in addition to sleeplessness, watchfulness, fear and worry.

Help in Meeting Extraordinary Economic Costs and Losses

The true cost of caring for a child with a disability or a special health care need is not readily calculated. The medical costs (paid, unpaid, met, unmet, preventive, interventive, deferred) can, with difficulty, be calculated. The true family costs remain totally uncalculated. The amount that the public systems provide to any one child or family is not ungenerous; the problem is that it is insufficient to their needs. Many families report that meeting 40% of the cost is very helpful but the other 60% may be an unacceptable cost. Alone, the first two months of a child's service may put a family into long-term poverty.

The downward economic slide can be rapid and severe. In one family, where both the husband and wife had full careers before their son was diagnosed as autistic, the husband reported losing, in 2 years, his well-paid employment and his ownership of his own home. His family is now on food stamps and in public housing, in order to enable him to be the 24 hour-a-day primary caregiver of his three-year old son and his recently diagnosed infant. There is no way he could continue his normal life and still provide his children with 100% of his attention 100% of the time.

> My life is watching my children. I had to take this role because my wife went through a major denial stage where she wouldn't help or do anything around the house. She withdrew.

Unless families are both well-employed and well-insured or are already receiving AFDC, SSI, and other public supports, they are inevitably to be bankrupted or considerably reduced economically within a year of their child's diagnosis. Those who are reasonably well-employed are not as well-protected as those who are well-insured; the costs of a child's care can quickly exceed a family's ability to pay for medical and other services out of pocket.

Parents suggest that they must give up everything to get help for one child with significant disabilities and special health care needs; some have taken specific action to reduce and then maintain their income at the poverty level. Most have moved rapidly and significantly down the economic ladder since their child was diagnosed, due to 1) high medical payments, 2) high non-medical support payments, 3) loss of employment for the primary caregiver parent, and 4) loss of savings accounts, home equities, trust funds, retirement accounts, college savings funds, insurance accounts, vehicles, borrowing ability, and other resources. Some of these families have become functionally impoverished; if not poor at diagnosis, they become poor following diagnosis.

Siblings The costs associated with the child with disabilities or special health care needs erodes the ability to provide for the siblings; they pay, in part, for the condition too, in terms of their own normalization and life opportunity. Parents reported their rejection of promotions and pay raises for the same reason. This results in demoralization, a stressor contributing, as does the child's condition, to family breakup.

Poverty resulting from the disability or special health care need results in downstream family problems as well as the family requirement to present themselves to other public agencies for services and supports.

What specific services and supports do the parents need?

Many parents claim to have become experts not only in the medical theory and practice around their child's condition but also in the organization of and access to services and support funds, maintaining mountains of files at home, as well as in the complex subjects of medical and life insurance. Those who have private, military, or other insurance have quickly discovered both the strengths and limitations of their coverage.

Income Most parents question the logic of basing public support, such as SSI, on the parents' **income** rather than exclusively on the child's **disability**(s) **or special health care need**(s). They feel that all children with disabilities or special health care needs should be directly supported, regardless of family income; they do not understand the linkage between the medical needs of the child and the economic life of the family. They note that failure to successfully hospitalize a child at home would cost government a great deal of money, in supporting the child in residential care or in a foster home. They suggest that government counts on the parents continuing in this under-supported role.

Medical Equipment

Parents expressed concern that public policy does not recognize the difference between their lives and those of people in general. For example, they do not understand why medical insurers and internal revenue policy do not recognize that items like diapers and certain foods should be treated as prescribed medical expenses, since their children cannot function without them. They also report that the public formula for purchasing equipment, like portable feeding tube pumps, often does not cover the cost of the equipment.

> What's the point of paying for only some of the cost if we don't have the money to pay the difference?

Medical Skills

Public health nurses (PHNs) and others note that, more and more, infants and toddlers with disabilities or special health care needs are being discharged into their parents' care with major medical equipment such as tube feeding and oxygen equipment. This places a great burden on the learning skills and energy level of parents and creates an increased need for skilled respite care, for which funds and persons are in very short supply. In other words, discharging children with skilled nursing care needs makes the ability of parents to get respite through unskilled personal care support (e.g., babysitters) virtually impossible. As more children with more acute care needs are discharged into their parents' care, with extensive medical equipment support, this problem will continue to grow.

Personal Support, Respite, Home-Based Services, Counseling

The families of children with significant disabilities or speical health care needs provide an intense level of home nursing, emergency, personal, and other care to keep these children safely at home. To provide this level of care, parents need, but do not receive, adequate personal support, respite, and home-based services.

Alternatives to home-based care are very costly, requiring round-the-clock medical, nursing, and physical therapy care, hospital or residential care, extensive use of the emergency room, equipment, and supplies for personal care -- medication, special food, diapers, and so on. While families can provide this care and reduce the overall cost of care (their labor, concern, and space being "free"), the families themselves are greatly stressed. Failure to support these families to reduce their stress results in family failures to continue as primary caregivers to these children and adults, shifting this responsibility to paid, non-home-based services.

Some key informants noted the following paradox. When highly skilled hospital personnel come to the end of their workday, they go home, they recreate, they relax. When the parents of children who are hospitalized at home end their workday,... it does not end. In order to meet parents' needs, parents require the provision of in-home supports:

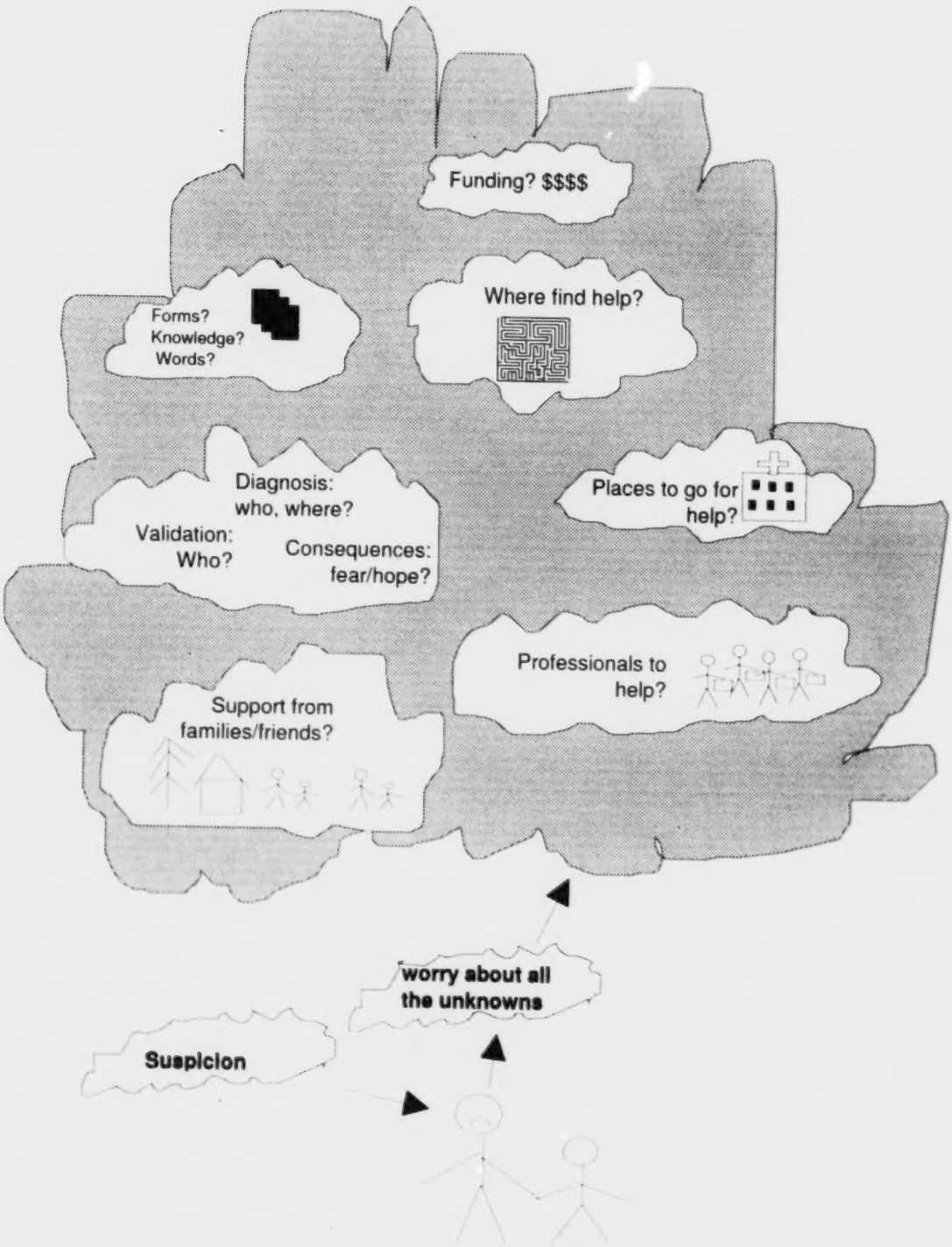
- paid, skilled respite care
- low-cost sourcing for new or reconditioned supportive equipment, individualized personal devices, and basic supplies
- emergency in-home intervention care
- prescriptions for basic supplies as medical supplies, such as diapers, for which some children have a long-term need
- marital and family counseling for parents and siblings of children with significant special health care needs
- mental health counseling (particularly grief and marital counseling) for parents and siblings of children with disabling conditions.

Among their greatest needs is the need for skilled in-home respite care, by licensed persons with the personal and technical skills and levels of personal responsibility to allow parents to do other things out of the house without worrying about the safety and well-being of their child at home. Even a short time free of hospital-like tasks would be perceived by parents as a great release. Yet respite care funds are in chronically short supply, as are skilled respite workers. Respite funds are released in blocks as they are appropriated. This results in long waiting periods for parents.

Parents report that the wait for respite care can feel endless; parents can be on the waiting list for a year or more. The assessment of need for respite care appears to be based on the condition or disability of the child more than the circumstances of the parents. The agency measure of parental need for respite appears to be the child, not the parent.

In the midst of all of these needs, parents turn to their family physician, to county public health services, to schools, to welfare agencies, and to friends and acquaintances for help. Because parents typically have no knowledge of the range of Birth to Three Services in their community, their search for help tends to be idiosyncratic and unorganized, resulting in delays in getting needed supports.

The Unknown


Funding? $$$$
Where find help?
Forms?
Knowledge?
Words?
Diagnosis:
who, where?
Validation:
Who?
Consequences:
fear/hope?
Places to go for
help?
Professionals to
help?
Support from
families/friends?
worry about all
the unknowns
Suspicion

How do public and private services respond to these families?

Different Services from Different Programs and Agencies

In each county, the providers demonstrated to us that there are many Birth to Three programs, services, and providers who are in place to respond to some of these family needs. Health, education, and welfare agencies have specific programs to deal, separately, with these needs. A range of public and private providers are generally available to provide needed therapy services for a range of conditions. In addition, there are Interim Family Resources Coordinators (IFRCs) and parent-to-parent support and advocacy groups to help these families become informed about and negotiate their way to these needed services.

Typically, each county has its own version of 26 birth to three early intervention services; each may also have Children with Special Health Care Needs (CSHCN); Head Start; First Steps; Women, Infants and Children, (WIC); Division of Developmental Disabilities, (DDD); Early and Periodic Screening, Detection and Treatment (EPSDT); public health nursing; maternity support; tribal clinics; Migrant Council; Child Protective Services, (CPS); Child Welfare Services, (CWS); child care providers, private medical and dental providers, hospitals, clinics, neuromuscular centers, neurodevelopmental centers, developmental pre-school, and more.

How do parents experience these services?

A "Maze"

This array of services is experienced by most parents as a maze rather than a system. Both parents and agency personnel report that it is easily possible to get "lost in the shuffle" and "fall-between the cracks" among programs and never get "plugged in." They suggest this results because, at the local level, the service array or network generally

- lacks a single clearinghouse for information
- lacks a single point of entry into services
- lacks a universal referral and tracking function
- contains a multiplicity of different
  - qualifications for service
  - eligibilities for service
  - definitions of the problem (e.g., medical, family, community, welfare, education)
- is marked by an unwillingness by many providers to refer to the public network or to accept low reimbursement rates for their services.

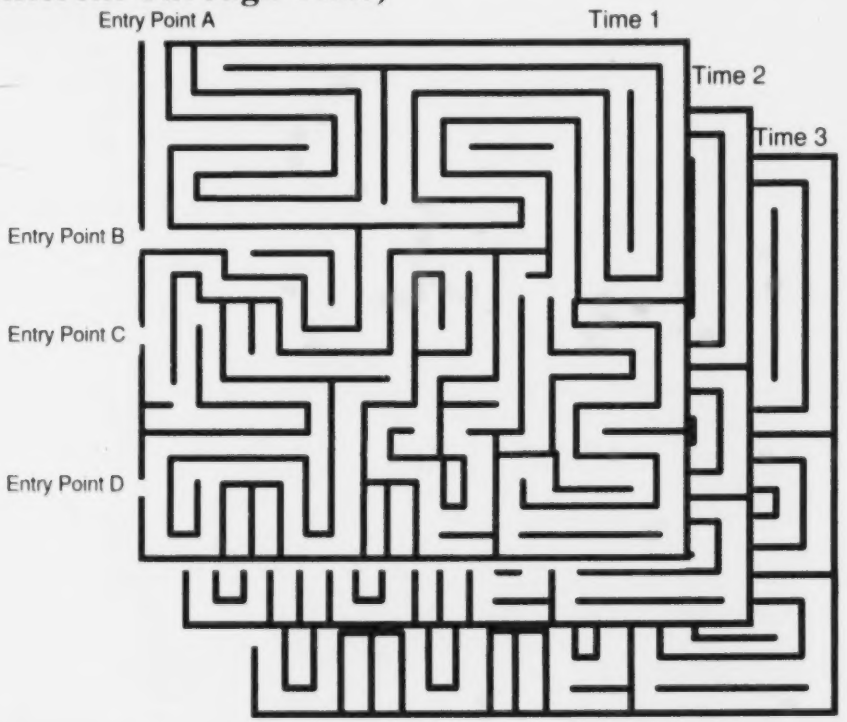
With Gaps in Needed Providers and Services

What is also generally agreed upon is that:

- there are not enough providers by location, by specialty area, by level of skill, and trained to this 0-3 population; this results in often significant delays and waiting periods for certain treatment services or underservice in receipt of services
- there is not enough funding, from all sources, to fill these recognized gaps
- there are needed services that lie outside those legally mandated (e.g., grief and mental health counseling for parents)
- there are major service gaps for those children whose condition is defined, primarily, as behavioral
- services, other than tracking, are not provided for those children who have been assessed as only "at risk" for delay

Few parents or agency personnel at the local level talk about their Birth to Three Services as a "system". System implies coherence, coordination, rationality, minimalism, organization, and efficiency. In fact, however, the array of such services, at the local level, really appears to be a loosely affiliated, somewhat fragmented maze, comprised of unequal parts of categorical funding, multiple programs, multiple eligibilities, under-funding, difficult coordination, and significant decentralization; it appears to operate better in some counties than in others. Nonetheless, many parents and providers suggest that the local system is an endless maze which must be learned, mastered, and relearned by families.

Array of Services Perceived and Experienced as a Maze (Different Through Time)



Parents suggest that the **availability** of funding sources and local providers is not matched by local service **accessibility**, **adequacy, appropriateness**, and **equity**. Families may have to fight and plead for what is promised to them in policy. This makes increasing the ability of some families to make more effective demands on the system a critical element in any one family receiving services. It also raises two key questions:

Why do systems operate in such a way as to make some families more likely than some others, similarly situated in terms of medical needs and financial condition, to receive needed services?

Why should government have to underwrite services to overcome barriers in other government-funded programs, rather than changing those programs directly?

How do parents approach the services?

Trial and Error

Because the local Birth to Three Services appear as a number of loosely-linked service pieces, parents will begin their quest for services at a number of different, even arbitrary, points, then seek the others one at a time if and as they are told they exist. Instead of experiencing the entire service array at once, families approach each service or program one at a time, in the correct or incorrect order.

Variety of Entry Points

Children and their families can touch and perhaps enter the local system through a variety of points and routes—hospital maternity room, WIC, public health nursing, pediatricians, other physicians, day care, school, screenings, child welfare and child protection services, hospital emergency room, neighborhood health clinic, agency advertisement, community screenings, self-referral, childfind, and home visits by agencies for these or other purposes.

The issue is less what the first point of contact is than what happens at that point to attach them to a network or clearinghouse of information, support, and referral. In a number of locations, these various points of entry do not have universal linkages to that network nor provide total and systematic access to all information about resources.

While key informants suggested that poverty, language, education, services shortages, and transportation are major barriers to service, at the local level, there are often more narrowly- defined barriers. While there are shortages of providers, money, and other resources in early intervention services in all counties, the major issue in services does not appear to be "availability" but local "accessibility", that is, **the ability to pass from non-service to service.**

Families Discover Many Gates to Service

There is a general impression among key informants that the needed services are available, but

> the doors are shut, so that the task for parents is to either open the doors or get around the doors.

They suggest that, for some families, there are gates to the services which are either shut or difficult to pass.

Any impediment to service controlled by a policy, procedure, eligibility or by another person can be a gate. These impediments to service are legitimate in that they ensure that resources are expended only on those persons whom the underlying legislation and appropriation have intended to be served and that scarce resources are not wasted. Policy, procedure, and persons are put in place to ensure that the gate functions as intended by the mission of the agency.

Policy and procedural gates are often assumed to be neutral or blind to "person". However, many respondents suggested that certain aspects of gates were, in fact, selective against certain child and parent attributes (such as educational level and ethnicity). Gates controlled by another person were often seen to be very selective.

> Much of service depends on who you are and who you get.

Every agency has someone who performs gatekeeping functions, whether a professional, a para-professional, or a clerical person. Because of the small size of most early intervention services, even within very large agencies, quite often "agency" is reduced to "person". In other words, for all practical purposes for the parents seeking services, the gatekeeper **is** the agency. Gatekeepers' skills, attitudes, and knowledge were seen to determine the future of a family's care, more than "the system" above them. One mother noted that the service system, as experienced, is really the sum total of key personalities at each of the key gates.

At the most local level, where parents and agency staff operate, early intervention services constitute a "person-based" system. The important assessment, planning, referral, and coordination interactions are less among agencies and institutions than among individual parents, providers, gatekeepers, parent groups, and so on. This is a "person-dependent" service arena. If one has a good service coordinator, gatekeeper, or network of agency personnel, the system can work; if one has an inferior service coordinator, gatekeeper, or network, the system cannot work.

How Significant are these Gates?

One critical component of gates **is that they are selective**. Agency respondents suggested that certain persons with certain attributes get through while other similarly situated persons with different attributes are rebuffed, challenged, or long delayed. If two families with children with similar medical conditions and financial eligibility but different attributes have different passage experiences at the same gate, what is it about the gate that selects for or is sensitive to these other attributes? Are these considerations legitimate or illegitimate, correctable or not correctable? To the degree that the selectivity bars those with legitimate claims to service from receiving service, they can be considered **barriers to service**.

The operations of some gates may result in the selective denial of timely access to needed information or services. The resulting task for parents and referrers is to either pass through the gates or get around the gates. Some gates are reportedly so difficult and frustrating that they deter some families entirely from seeking services. These simply self-select out of the pool of claimants. While this certainly protects the agency's resources, it does not meet the agency's mission of service.

A child is considered "served" if he or she has been found, screened, assessed, provided with an individualized family service plan (IFSP) or individualized education plan (IEP), and referred to some service. Getting to this point clearly means passing these gates and perhaps many others, if the family has tried to enter the system at the wrong gate, that is, a gate not leading directly to the early intervention service and parent support network. However, once having passed these gates does not mean that a child has now entered a gate-free service environment and is receiving services; it means only that the child and family are approaching one or more new gates to treatment. Passing the first gate may or may not be helpful in passing the ensuing gates, since each of these has its own rules, procedures, demands, standards, forms, and often autonomous and unmonitored gatekeeper.

What are the Key Characteristics of these Gates?

The key informants provided very similar information about the characteristics of gates which affect the way they operate in the real world of services:

INEVITABLE

They are inevitable and unpreventable. For example, some services end at or before the child turns three.

REVERSIBLE

Their successful passage can be negated, if, for example, attendance or activity requirements are not met, if there is later family disruption, physical abuse, or substance abuse.

REPETITIVE

They may have to be passed more than once. Some gates, such as financial eligibility, may have to be passed several times, as the family income or diagnosis changes; having to re-pass previous gates over time results in disconnecting and reconnecting problems for parents.

CONTROLLABLE

They are limited by absence or constraint of resources (e.g., funds, available professional hours, appropriate professional skills and skill levels, equipment, and facility space).

They provide access to either funds or services or both; in some instances, while the parents have to access the services, it is the provider agencies who have to access the funds for the family.

They may or may not be visible to the passagee.

They may be within or without the control or influence of the passagee.

They may require legitimation by others (e.g., medical diagnosis).

STANDARDS

The standards applied at the gate may be fixed or discretionary and clear or disguised.

They may require certain attributes of the child (e.g., specific severity of condition) or the parents (e.g., lack of income).

They place specific demands on parents, such as language, patience, assertiveness, time expenditure, accommodation to delays, or tolerance of frustration.

They may be collectively determined, where the passagee sees himself in solo passage, but the agency may be juggling many passagees and a limited resource base at the same time.

DELAYS

They may have very long waiting periods for decisions and/or actions. The parents and child may have to wait at some gates for very long periods without any supportive service, even though they are experiencing stress and loss, due, for example, to delayed diagnosis or bureaucratic processing.

They may require multiple, linked, and sequenced actions to pass.

Department of Health Findings

The exploratory study confirmed Department of Health findings which appear in Washington State Department of Health Report, June 1993, that multiple gates appear in phases:

Obtaining Services: Phases and Gates

Finding Out Phase

Pre-diagnosis Gate (suspicion/concern)

Parent suspects problem
- seek information
- seek professional viewpoint
- seek professional review

Child find acitivities
- with screening program
- without screening program

Professional willing or unwilling to diagnose
- long waiting periods
- diagnosis delayed
  - not educated in this area
  - "wait and see"
  - remote testing site
  - child too young
  - disagreements in professional perceptions
  - long wait for referral to specialist

Still waiting or/searching for validation of suspicion

Suspicions confirmed by "professional"

"Getting Diagnosis" Gate (assessment and plan)

Seek Diagnosis/Assessment
Get Diagnosis/Assessment
Get Treatment Plan
Get Referrals

Suspicion is confirmed but no definite diagnosis

Diagnosis/Assessment and Plan Obtained

"Post-diagnosis" Gate (impact on child and family)

Families need information
- about child' condition (what is it? is it curable?)
- about future (do I have to give up my baby? will my baby die?)
- about available services and required actions
- about effect on family

No information on implications of diagnosis

Professional's capacity or incapacity/unwillingness to provide such information

Information Obtained

Obtaining Services: Phases and Gates

Getting In Phase

"Where to Go" Gate

finding a single entry/multiple entry points
finding a proper map of the system
* easily understandable
* with information on gatekeepers
* applicable to needs of child and family
* specifying rigidity/flexibility of rules
(some children in need fall between or outside of categories)
* finding assistance in "navigating" the system
("someone guide me through the maze")

Trial and error searching

Map obtained

Paperwork Gates
(access eligibility)

filing all relevant applications
* different agencies and sites
* time consumed in submitting and resubmitting forms
* culture and language problems
* different forms for different programs/funding
* changing guidelines and criteria

Waiting (more forms to fill, more clarification needed or rejection)

All forms submitted

Financial Gate
(financial eligibility)

finding funding sources
fulfilling funding eligibility criteria
* too well off to qualify -- too poor to pay
* change status to qualify (legal separation, loss of job)
paying some or all costs

No funding: can't pay/ too costly/searching

Funding Obtained

Referral Gates

No referral to specialist and/or support network

receiving some/all referrals

Referrals Provided

Program Enrollments Gate

Waiting to get in

Put on waiting list / accepted into program

Enrolled

Receiving Services Gate

Waiting to be served

* Special services/equipment
* local/non-local services
* home/office based
* respite care and/or day care

Served

Note: *Even after becoming enrolled and served, actual services provided vary as to their appropriate fit with child/family needs. The fit will vary due to local characteristics of services and providers.*

Obtaining Services: Phases and Gates

Getting What is Needed Phase

LImitations Due to Characteristics of local Services and Providers

- Sufficient/insufficient amount of particular services
- Sufficient/insufficient range of particular services ("best fit" versus "most appropriate" for health care needs)
- Culturally sensitive/insensitive
- At low/high costs
- Scheduled/not scheduled to fit child/family needs
- At convenient/not convenient locations
- Adapted/not adapted to changing needs through time

If family experiences limitations, options include:

A) Accept limitations
B) Refuse limited services/support
C) Move to other locality and/or search for providers that can deliver:
   - sufficient
   - accessible
   - appropriate
   - cost effective
   - timely and
   - continuous care
   - with family participation and support.

How do parents pass these gates?

In order to pass these gates, parents may have to

- learn and speak the required language of the agency and its gatekeeper
- master certain "secrets" and employ certain "tricks" through which agency barriers can be overcome
- alter the way they represent themselves and their children to the agency, both in person and on complex forms required by each agency
- increase their "voice" and "power" at the gate, by enlisting the support and skills of others.

See the chart on the following page depicting what determines passing through a gate.

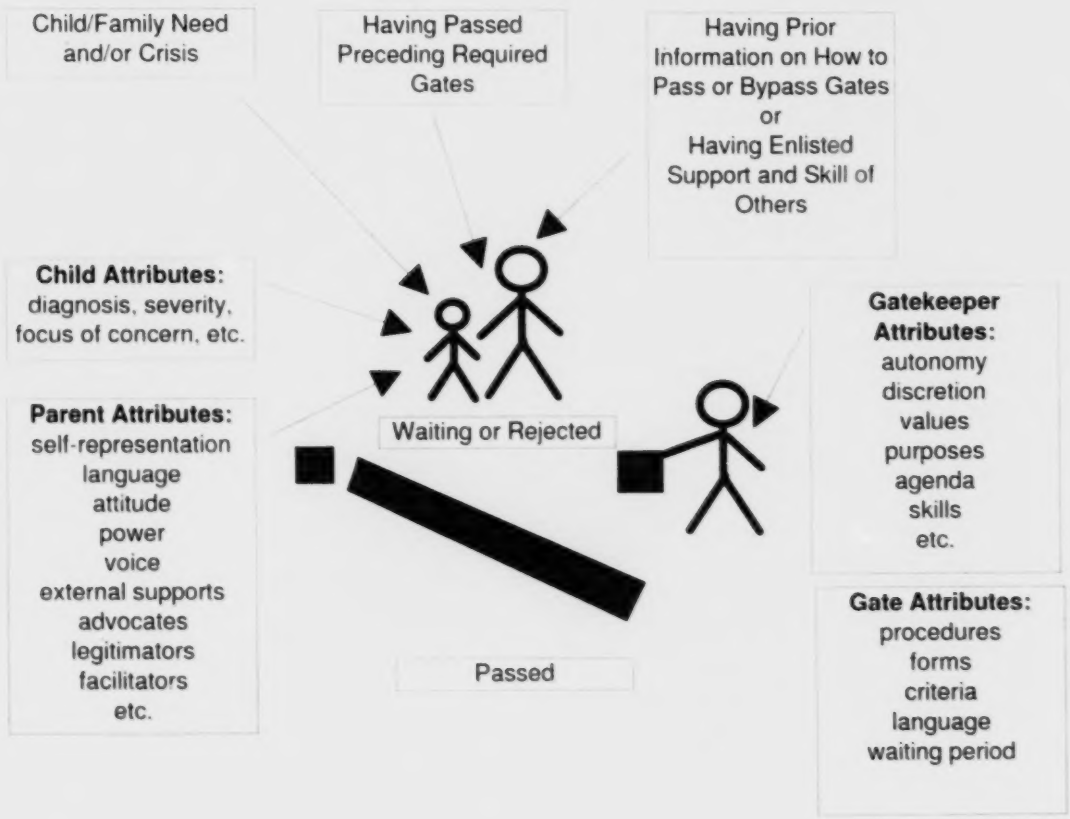
Self-Representation

Many service agencies and providers focus heavily on the self-representation of the person seeking entrance. Parents, parent advocates, and direct care staff agree that parents must appear a certain way, dress a certain way, use a certain language, and so on, in order to pass major gates. In many instances, parents must engage advocates, such as Interim Family Resources Coordinators, nurses, doctors, teachers, or other agents to surround the parent to make him or her appear to be what the gatekeeper requires. Parents express considerable anger and frustration that medical and other services for children with disabilities or special health care needs and their parents require high levels of self-representation and aids to representation, when the mere presence of a serious diagnosis, the obvious material costs of its treatment, and the associated human costs to families would have made extensive self-representation at a gate seem unnecessary.

Regarding gates, one public health nurse noted that

> If there are eight different gates, there are eight different shapes. The family has to know the game, that is, which shape they have to project to go through which gate. 'In this gate, I'm a square, in that gate, I'm a circle.' One shape will not serve all gates. What case management does is go with the family to the gate and presents them as a circle. If we didn't have to do that, we wouldn't have to have case management.

What Initiates and Determines Passing a Gate?


Child/Family Need and/or Crisis
Having Passed Preceding Required Gates
Having Prior Information on How to Pass or Bypass Gates or Having Enlisted Support and Skill of Others
Child Attributes: diagnosis, severity, focus of concern, etc.
Parent Attributes: self-representation language attitude power voice external supports advocates legitimators facilitators etc.
Waiting or Rejected
Gatekeeper Attributes: autonomy discretion values purposes agenda skills etc.
Gate Attributes: procedures forms criteria language waiting period
Passed

How do parents learn about what is needed at gates?

From "Patchwork" to "Blanket"

In some locations, while the array of Birth to Three Services is seen as a patchwork of pieces, the county agencies are seen by some parents to have created something they call an "umbrella" or a "blanket." To create a "blanket" out of a "patchwork" requires some "stitching". There is agreement among key informants that birth to three enhancements have resulted in methods to tie the seams of services and programs together for individual children and families. Informants variously call this the "needle", "threads", "glue", or "fill-in" required by the gaps in the patchwork.

"Stitching"

This required "stitching" process includes such features as interagency coordination, collaboration, and case management. The costs of such required coordination as a general interagency burden and for each interagency or multidisciplinary effort on behalf of an individual family are high. The costs are tangible, because coordination requires commitment of paid staff hours, hours seen as taken away from direct client contact hours. The benefits are also seen as tangible, particularly when agencies agree to blend their efforts and funds on behalf of specific classes of clients or individual clients.

IFRCs

IFRCs (Interim Family Resources Coordinators) are professional and paraprofessional community workers employed by provider agencies or parent advocacy organizations through contracts with the state. Their tasks are to support families, to seek and provide information about community organizations, to ensure screenings and assessments, to prepare individualized family service plans (IFSPs), and to refer to community and agency resources. Their roles in the service system are "interim" in that their active involvement with parents is intended to be short-term, generally two or three months, until these families are made eligible, attached to services, possess an IFSP, and are receiving case management services from a service provider without existing state programs.

IFRC Roles

IFRCs fill an important gap between the Birth to Three Services provided by agencies and services and the parents of children with disabilities and special health care needs. They are variously described as "stitching" for the patchwork of services, as intelligence agents, as parent advocates and empowerers, as referrers, and as case managers. In their role between agency and parent, they learn and transmit the many techniques required to pass gates and arrange for parent supports at the gates.

> They think we have the 'in', the inside track to getting what we need. All we can do is share what we have found to work for us.

IFRCs suggest that there are hundreds of secrets in these service gates that parents need to be informed about.

> For example, not everyone knows that you can use family support dollars for other things than respite. Just because it authorizes you for 33 hours of respite does not mean that you have to spend it that way. You can spend what you don't need on diapers, since they are required but not considered a medical supply. You tell them to ask for twice as much respite as they want, because the agency only authorizes half of what is requested. That's the kind of information you need to give them.

Skills and Compensation

The IFRCs we interviewed were mothers of children with disabilities or special health care needs. A number of them were heavily involved in multiple volunteer organizations, advocacy activities, groups, and committees, outside of their paid work but on behalf of the same class of parents and children. Most seem to be paid relatively small salaries, commensurate with being para-professionals in this role; many, however, are or have been successful professionals in other settings (e.g., teachers) and entrepreneurs. Most seem to be very capable persons. For many, this paid work with parents on behalf of their children has become a calling.

The IFRC system, as it currently exists, appears more of a partially subsidized voluntary program than an agency-like program. Given the rate of pay, para-professional job description, long hours, stressful work, community (rather than office) presence, and family experiences of most IFRCs, most appear more like the best of community volunteers than lower-level employees.

For example, one IFRC, in order to obtain this work which generates $1200 a month, pays out $600 a month in child care, loses $200 in SSI, loses CSHCN funds which pay the cost-share for her son's equipment, and has added clothing, transportation, and related expenses. These combined losses, together with time away from her own child, make her question whether she should continue in this role.

Pressures

While advocacy and case management are outside the formal roles of IFRCs, some IFRCs feel they must advocate directly for individual parents and children with agencies, particularly with DSHS divisions and schools. The advocacy is, generally, not confrontation but representation and coordination,

> to help back them up if they can't do it all themselves. I'm going to protect the kids and if their families can't take a step to help the kid, I will. Some families just don't have it together. Some don't have it together at this point in their lives, some don't have it when dealing with agencies, most don't have it with either. Some are just petrified and need information before meeting with agencies. For example, one young mom had a scheduled school conference with the principal and a counselor. When we walked in the room, there was the principal, the vice-principal, the counselor, the playground aide, the teacher, and one other person. If she had gone in alone, she would have been totally intimidated. I was intimidated. The school people were good and said that we could ask any of them to leave and come back later. But, as a parent, would you actually say, 'Yes, some of you go away'?

Although not services professionals, IFRCs can help to bump families up on some waiting lists, by "calling in favors." This tends to be based on the personal regard by the gatekeeper or physician for the IFRC and must be very sparingly used. Personal regard is constructed on contacts built up over time, contacts outside of the formal IFRC-provider environment (e.g., serving on committees together), and on other long-term relationships (e.g., the physician is also the caregiver for the IFRC's child). Personal regard depends upon

> how you handle yourself and what you look like in your repeated contact with them.

The role of and reliance on resources coordinators suggest that the Birth to Three Services system requires a "counter-industry" to help parents overcome the barriers within and between the various services. However, the IFRCs can function only within the conditions set by the patchwork of services; while the IFRCs can stretch the responsiveness of the system to its maximum, the IFRCs can neither create new services nor overcome the absolute conditions at certain gates. They can and do, however, often create and unite a larger voluntary base in the community, through collaborative outreach activities and support of parent-to-parent groups.

How much do parents rely on other parents?

Sharing the Status of "Survivors"

While parents come to Birth to Three Services one at a time, based on an awareness and acceptance of the reality of their child's diagnosis, most parents cannot survive or succeed in isolation but need the support of other similar parents. These parents suggest strongly that only a parent of a child with disabilities or special health care needs can help a parent with a child with disabilities or speical health care needs. The "survivors" hang together, mutually supporting each other, rather than drawing on the larger resources of "normal" families in the community. They form a sub-culture, relatively invisible to the outside, but with powerful bonds formed from the reaction to and manner of surviving their situations.

This does not mean that these parents, families, and children are similar. Similarity of the child's condition, socioeconomic status, and so on appear far less significant than the parental determination to survive and their methods of survival. It is not only the families supported by **public** early intervention services which need information and support; **all** families, regardless of employment and insurance status, require more than is available within their family and friendship circle.

Parents, both single and married, do for each other what agencies can not and perhaps should not do. Many of the parents with whom we spoke live at great distance from their extended families, neighborhoods, friends, and communities of origin. Thus, they have to reconstruct family and community where they are. Even those who have both family and community nearby report overextending these persons rapidly.

Mutual Support

Parent-to-parent groups, IFRCs, and some personal support groups reconstruct for families what would otherwise be provided by community, neighborhood, and extended family. Survivors insist that what separates them from parents who somehow fail to survive is the support of family, employers, and friends, most often friends whom they find **after** their child is diagnosed. These friends form an invisible "village" or set of villages within the larger community, mostly informal and personal, to collectively manage their way through these problems. Their mutual support is immediate, relevant, nonjudgemental, and unstinting.

> Nobody else knows what it's like; only they can help in a way that nobody else can. Only they can hear me say that I wish my child had died and not consider me scum. They only say, 'You, too?'

> Every parent of a handicapped child thinks, every once in a while, that it would be nice to give the child back. In adoption cases, this is more real, because you really could. It's important to be able to say this and not be blamed.
>
> With these people, I can tell them anything and they will not reject me. They're going to tell me when I'm off. They're going to confront me when I'm self-pitying. But they're going to support me when I'm down.

Different from "Normal"

While important friendships often result from this mutual support, the key to parent-to-parent is that they share conditions which set them apart from "normal" families.

- their infant or toddler is experiencing a significant disability or special health care need
- this condition has profoundly affected the parents' view of themselves, their careers, their marriage, their child, their dependency, and their future
- many sense that they and their child are not valued by family, friends, and community, that they are no longer seen as being on the ladder to normal success, and that they are "stuck" forever in their present condition
- many sense that they are blamed for their child's conditions, appearance, and behaviors .

But Valued Within the Sub-Culture

These parents feel both rejected and in need of some validation and appreciation of their life choices, their values, their identities, their customs, and their actions, all of which are embedded in the condition of being a parent of a child with a significant disability or special health care need. Feeling rejected for being "different," they feel they need to be appreciated because of this difference.

As a consequence, these parents together begin to create a somewhat distinct culture, with a language, a way of communicating, a set of values, stances, norms, and skills, an array of daily activities and tasks, a point of view, and a set of intensely intimate and mutually supportive relationships that distinguishes them within their community.

For example, one small group of three mothers, each with more than one child with a significant disability, work together to provide respite for one another. They parcel out the children in clusters, so that one mother may either have respite or have the time to take one child to treatment. They take their entire families out to fast food restaurants and sit together to have more normal family recreation. They camp out and holiday together, so that they do not bear the onus alone of other people staring at them, avoiding them, or commenting on them because of the behaviors of the children.

Achievements

In sum, then, the larger human services system has created a set of conditions and eligibility formulae to be applied by local agencies attempting to create individualized packages of services specific to the individual array of needs of each family. In doing their work, local agencies have erected a series of more and less difficult gates for parents to pass. The gates to service have engendered another sub-industry of parent volunteers and near-volunteers who supply parents with the secrets to pass or defeat these gates.

This parent sub-industry is a vast informal network of persons and communications which collects and shares these secrets and acts as community, neighborhood, extended family, and friend for those families who require this kind of support and sense of belonging. Together with the inter-agency coordination and IFRC efforts noted above, this culture can provide supports and potential solutions for individual families.

Limitations

Key informants suggested strongly, however, that the combined efforts of IFRC's, agency case managers, inter-agency and multidisciplinary teams, and parent-to-parent supports do not overcome more basic system problems, such as

- lack of needed levels of respite care
- restrictions on the use and receipt of categorical funds
- formal and informal waiting lists (or their equivalents) for local treatment and respite services
- the standards for eligibility and qualifications applied at service gates
- the lack of mental health, marital, and grief counseling for parents
- the unwillingness of some providers to refer to others and/or to accept low reimbursement rates for their services.

How do localities try to improve their services?

The forces which result in the creation of services and program gates and community responses to gates are, essentially, based on limited system-wide resources. Agencies, local providers, and volunteers acknowledge that they have limited capacity to achieve major improvements; their efforts seem focused on smaller targets which demonstrate that today can be marginally but measurably better than yesterday, within fairly rigid constraints. Because they cannot significantly add to local resources, they appear to function within an essentially "zero-sum" situation.

Shifting the Paperwork Burden

The appearance of the sheer number of gates may be reduced by Birth to Three Services personnel who expedite or carry more of the paperwork burden for establishing eligibilities and qualifications. While some service agencies have managed to streamline and compress the paperwork burden by either administrative consolidation or absorption of the burden, it seems that relatively little of the true volume and detail of paperwork required by gates determined by categorical funding or agency can actually be reduced or eliminated. Each system has its own, seemingly irreducible, demand for forms. By filling the paperwork out themselves, the agencies mask the true size of the paperwork burden from the family but absorb a tangible cost.

One-Stop Shopping for Services

Some counties are, in one way or another, trying to simplify and centralize not the entry points but the initial gates which qualify children and families for service. In one county, a major urban community hospital is creating a "one-stop shopping" approach to most needed services. This approach is comprised of the following linked elements:

- blended programs
- a single intake form
- professionals as gatekeepers
- co-location of public and private Birth to Three Services

This planned co-location is viewed by some as a medical mall, containing separate but associated public and private services (e.g., nursing assessment, family therapy, grief and loss training, Headstart, hearing and speech, therapeutic child care, mental health services, DCFS, and so on). Planners intend for it to be a convenience to families to whom it is available.

Sponsors believe that proximity itself will create a more seamless relationship among providers serving the same children and families, present the possibility of a shared base of client data among these providers, and increase inter-agency cohesion, collaboration, communication, and case coordination. However, they are also clear that the eligibility and qualifications standards applied at each gate by these programs' gatekeepers in the service mall will remain unchanged from what they are now. Co-location does not create the ability to bypass any of the requirements posed by each program, project, service, categorical fund, or institution.

Is health care reform an answer?

Those parents who are dependent largely on public programs express great dissatisfaction with the obstacle course attached to present forms of categorical funding. Yet their concern about health care reform is, regardless of difficult eligibility gates and the current insufficiency of funds, what will happen when they are covered under individual or family basic health plans?

Fear

Their fear is that the funds to underwrite the reform package may be taken directly from categorical programs, so that they cannot do better than break even and will likely lose in the exchange. Parents read and hear about the individualized health care packages designed for "normal" persons, families, and conditions, not for those families with children experiencing significant delaying or disabling conditions. They fear that reform initiatives will, in the end, reduce their current, if still inadequate, level of support, and that families "will be jumping out of the frying pan into the fire."

Parents see health care reform, at both the state and federal levels, as providing

- fewer options
- fewer and tougher gatekeepers
- fewer alternative gates
- reduced ability to appeal from a gate
- less willingness of gatekeepers to refer to other services
- overemphasis on cost reduction
- a more medical than family-centered approach to disabilities.

Parents ask many yet-unanswered questions:

Funding Caps

Will these basic plans be capped, with no help once the cap is reached?

Will the total amount of resources expended on or available to this special population be increased, decreased, or capped at current levels?

Will their future be a combination of individual package and special categorical funding?

Will they be able to purchase or will the government provide or underwrite a catastrophic coverage beyond the basic health care plan which will cover the lifetime medical needs of their children?

Will these insurance packages exclude pre-existing disabilities or require a waiting period for such coverage?

Continuation of Current Support

Will existing special programs which now fund their children be phased out, so that when their cap is reached, there will be no alternative funding sources?

Will the Birth to Three Services wither away and be replaced entirely with personal basic health packages managed by remote care managers?

Additional Supports

Will these packages contain anything beyond medical benefits, such as mental health and marital counseling and respite care?

Will children with behavioral disorders or those at-risk due to environmental problems receive any more services than they now have?

Control over Services and Access

Will families be able to select physicians based on their combination of specialized skills and empathy with the family?

Will parents have to prostrate themselves before care managers in order to obtain needed services?

Will there be an appeal process from the decision of care managers and other gatekeepers?

The culture of families with children with disabilities or special health care needs has constructed a set of techniques for dealing with the agency systems and representing themselves to it. Like any minority culture dealing with a more powerful culture, this culture learns and speaks the required languages, wears the required dress, modulates its assertiveness, and shares secret ways to bypass seemingly impassable gates. Its limited strength is based on a continuation of the current patchwork of constrained but somewhat unmanaged care.

Health care reform threatens that base of knowledge and skills built up over time within that culture.

By individualizing the client population and possibly reducing the variety and size of categorical services, families see that they may be no longer effectively supported by their culture and that their thin base of control may be lost. Parents are very concerned that, having painstakingly learned the secrets and byways of the existing system, they will have to start anew in the reformed system. Once they are in a single managed-care system and have encountered a roadblock, they fear, there will be no alternative byways, techniques, providers, and "strings to pull." In particular, they feel that, absent the parent-to-parent support network which helps them now, they will have to face their idiosyncratic situations alone, without the benefit of collective secret information.

Note: Particular findings, dealing with gates, reimbursements, inter-agency conflict, and perceived causes of underservice and unservice, are described and discussed in far greater detail in the Source Document, "Birth to Three Early Intervention Study: Enrollment of Children in Disabilities and Special Health Care Needs in Washington State Public Programs", which is available upon request from the Office of Research and Data Analysis.

Part 2
The Experiences of Families in Different Populations

In Part 1, we highlighted the experiences of families in general with early intervention services.

We now turn to specific findings on the experiences, strengths, and weaknesses of families within particular populations and services locations in Washington counties. We discuss some discovered features of:

- rural and urban locations
- poverty and special populations
  - economically poor families
  - Hispanic migrant families
  - American Indian families
  - military families

What are the differences between rural and urban areas?

This section discusses the differences in service which are related to the condition of location, that is, where the child and family reside and where the services are provided. From our interviews in a few counties, we found that there are great differences in how services are provided in different locations. These differences may be ascribed to differences in:

- rural and urban areas and communities
- densely and thinly populated areas
- large and small communities
- geographically distant communities
- county composition and history

Location includes those characteristics of place and services in that place that make services more or less available or accessible. Few areas, if any, provide all needed services. Where one lives is likely to limit the completeness or appropriateness of services one may receive.

On the basis of our limited exploration, urban areas seem rich in services, but poor in community support and inter-agency and parental networks. Rural areas seem poor in services, but rich in community supports and networks. Rural areas appear to stitch services and supports together more routinely than do urban areas. While there were significant differences between urban and rural counties (in terms of resource wealth), there were comparably significant differences between the urban and rural portions within the same counties.

Rural Conditions Rural areas are marked by certain conditions:

- dispersed populations and services
- fewer home-based services
- difficulty in obtaining required frequency of services
- less ability to "compare my kid to other kids"
- marked more by "best fit" than "correct fit" services
- informal interpersonal relationships among agency personnel
- limited range and level of required assessment and treatment skills
- lower ability to meet very specialized needs
- higher costs of collaboration and coordination, due to few staff and time-consuming transportation
- fewer and more burdened providers.

Urban Conditions Urban counties are marked by certain conditions as well:

- higher technology
- wider array and higher level of specialization
- more rapid communications and transportation
- more extensive services for the more severely disabled
- concentrated services and lower travel costs
- more intensive emergency care
- more expensive services
- more extensive inter-agency formality and competition
- high turnover rate among service workers
- more alternative service resources.

What are the Strengths and Weaknesses of Rural Settings?

In brief, urban **versus** rural location seems to determine or is directly related to the range of services, the skill levels of practitioners, the cost in transport to services, and the ability of practitioners to effectively construct and maintain birth to three services networks.

Rural services appear better at finding and maximizing their resources within the greater community than are the urban services which tend to rely more or solely on the agency and provider service system.

Intimate Service

In smaller rural communities, child developmental services are commonly consolidated in a single, multi-program child center. In smaller communities, the IFRC works with a small stable team of therapeutic specialists; the communities usually have little redundancy in services. The same multidisciplinary assessment team may be also the planning team, the coordination team, and the service team in the provision of services.

The experiences of services in rural communities where the birth to three services are geographically proximate are that coordination and communication are, in fact, easier. It breaks down many agency and disciplinary boundaries and highlights some others. Agency personnel readily acknowledge that the ways in which "inter-agency" works in the rural and urban areas of the county are very different, that rural areas are:

> much more mellow, there is a different attitude, they seem to want to work things out. Given similar situations but different players, things can go either amazingly well or entirely to pieces.

In smaller communities, referrals are generally made to specific agency persons, not merely to the agency or unit. In these locales, where most umbrella services exist in physical and social proximity to one another, parents seem to be referred from one service to another with easy informality.

Rural care is viewed by some as better, due to smaller numbers of children with disabilities and their higher visibility in smaller communities, more effective inter-agency collaborative network, and more effective public health nursing, even in the face of fewer available or accessible specialist-providers and lower skill levels.

School-Based Services

One key attribute of location is the presence or absence of school district services. The decision to provide such services is likely to be based on cost, the number and coverage of providers already in the area, and urbanism. The more rural the community, the more likely that schools will provide these service functions in the absence of other providers. Variable lack of services can be pronounced within a county when only some school districts provide birth to three services.

The philosophical emphases of county programs differ significantly depending on in which "lead agency" they are centered or housed -- schools tend to be more child-focused ("they are all students and they all have IEPs") and public health agencies to be more family-focused. On the other hand, if the schools are committed to year-round services, they provide greater continuity for these children; in the counties interviewed, most, however, do not appear to have made this commitment. Other public agencies seem to try to fill this summer gap via limited individual interim service plans.

School districts vary widely in the availability of facilities for developmental pre-school services. Unavailability was reported most often in the rural school districts, even though group size may be very small (commonly fewer than 10-12). In addition, the costs of equipment are high. Transportation costs for school districts serving widely geographically dispersed families with children with special needs are also high.

Some school districts which provide services to children will provide services to children from other school districts which do not offer services, but only if they have available staff and can maintain quality of service.

Rural areas may experience greater difficulty in recruiting and retaining adequately trained specialists for infants and toddlers than urban areas, which are also caught in the grip of nationwide shortages. It is difficult to justify the costs of such skill levels and therapeutic and cultural expertise for so few children, even if congregated in a single facility. There is also great concern that teachers trained for early elementary special education have skills and techniques that are not developmentally appropriate for or transferable to these infants and toddlers.

Transportation as an Impediment

Transportation to services is seen as a significant impediment for some families, particularly, but not only, in more rural areas. The key here is not whether the county or community is deemed rural or urban, but the actual distance between a family in need of service and where the service is. Travel time and costs are also critical considerations for providers delivering home-based services. While in some areas the travel times to services are extremely long, thus inhibiting services for some rural residents, in other counties the distance between urban and rural appears to be more psychological, for both residents and providers.

Where one lives limits the completeness of services one may receive. More rural areas, with communities (and their services) separated by long road distances, require routine access to a car and fuel. For the more geographically remote families or those with children with complex needs requiring more distant specialized services, the travel costs can be considerable. For example, in some areas, driving times of four hours each way are not uncommon, usually requiring overnight stays as testing usually requires the child to be rested.

The other true costs include

- acquiring an appropriate car or van
- acquiring appropriate equipment in the vehicle to sustain the fragile child during travel (e.g., seats, portable feeding and breathing equipment)
- travel costs, including lodging and food
- confronting road dangers (e.g., fallen trees and rocks, snow, ice, isolation, lack of emergency road services, curves, timber trucks), and
- the time away from work and family by the parent.

Transportation is a major issue for more rural counties and communities. While some have para-transit and school bus/van services, they do not always move when children need to move. On occasion, families have missed major appointments because the transit system forgot them. It is an issue of mutual concern for parents and case managers.

What are the Strengths and Weaknesses of Urban Settings?

The cities in all counties we visited appeared more similar to one another than they did to the more rural communities within their counties. While the county systems centralized in the cities served the urban populations, the net effect of urban organization of resource-rich services did not seem to much affect what occurred in the rural communities in the same county.

In most counties, the basic services are concentrated in the more urban communities, particularly county seats, with considerably less available in the small towns. The issue of serving the more distant and smaller populations of counties is not resolved; neither itinerant services from the county seat nor satellite services in place in the smaller communities really seem to address the service issues. Both appear to be expensive and partial solutions.

Urban areas are typified by compactness of services, which means more and higher level services concentrated together in a smaller geographic area. Transportation is a less significant obstacle to service in urban areas, but it is expensive to transport disabled children even in the most urban areas. Urban areas are also typified by complex formal relationships among agencies and providers and their staff. Parents and providers generally suggest that urban services are more plentiful and varied but less personal and that it is far more possible there for families and children to fall between the cracks among the services and disappear.

What Happens Between the Larger and Smaller Communities in the County?

Public agencies tend to focus on children born in the major communities of the county. There, the confluence of medical recognition of problems at birth, multiple service agencies, a variety of hospitals and private providers, and the comparative ease of establishing "focus of concern", makes the aggregated services look like a system. By comparison, the sensitivity to early disabilities of special health care needs may be very different in a small community medical facility, with case workers having large and geographically dispersed populations, as well as mixed adult and child caseloads, and fewer resources.

The largest community in the county is, generally, the major beneficiary of birth to three services. Residents of the much smaller and more remote communities do not always benefit from these county services unless they move to or visit these more urban service amenities. If the birth to three services are consolidated in the urban community, in a major center, without comparable services provided by the rural school districts, these children have even less opportunity to be seen. Where one lives in the county is, indeed, a powerful determinant of the services one can be aware of and access.

Agency respondents viewed the same general phenomena very differently in the same county. In particular, providers serving ethnic or rural populations viewed the centralized urban services very differently. In examining their interviews, it seems clear that each uses different yardsticks to measure success and that each comes from an agency with a different voice and history in dealing with centralized services. Most do, agree, however that centralized services, while good for urban populations, do not, alone, meet the needs of rural populations.

The differences between urban and rural are widespread with offsetting strengths and weaknesses. The point here is not only whether each poses a problem for entry to services, but that these basic conditions are not susceptible to re-interpretation by families or gatekeepers.

What Roles do County Organization and Characteristics Have in These Services?

Counties differ in the degree to which they have a history of multidisciplinary, specialized, funded, consolidated, and coordinated health and human services to infants and toddlers with disabilities or special health care needs. It cannot be assumed that these are characteristics of either urban or rural counties; rather, they seem associated with the history, demography, and political character of the county, including

- community growth and population turnover
- institutional personalities and power structures
- personal and agency biases and values
- willingness and unwillingness to change/innovate
- local attachments to past solutions and models
- awareness level of this service area
- community culture
- personal networks.

While counties generally provided similar pieces in the services environment (e.g., IFRCs, DD centers, PHNs, school programs, hospitals, etc.), the ways in which these pieces were organized and functioned with one another were quite different among these locales. It was not considered either possible or fruitful for us to attempt to compare these counties directly to each other, since each presented a different array among the following elements:

- organization among and within service institutions
- geography itself (e.g., non-rational placement of services vis-a-vis populations and transportation systems)
- the cost (in time, money, scheduling) of transportation to services
- the range, array, numbers, and level of practitioner skills
- sufficiency of training
- presence/absence and competence of service networks
- physicians' knowledge of and concern with these problems
- presence and effectiveness of families on behalf of their children
- outreach and child-find efforts
- degree of targeted inquiry into the relationship among the existing inventory of services, the presence of children in need, and the utilization of the services
- sufficiency of case management resources
- the degree to which early intervention services personnel pursue children and families who are in service, but are "non-compliant."

Agency pursuit of children and families can be either a network policy as it is in one community or, in another, "it depends if someone takes a special interest." In another county, which appears replete with an array but not a supportive network of services,

> it depends on the family. If the family is effective, the system is there for those families. It's like a supermarket. But if the family needs extra help, the system hasn't been built for that. The most competent people find the services, the less competent people find the holes. Those who are competent but in serious crisis do not find all of the services either.

Poverty and Special Populations

The following sections discuss some of the special features of families in client populations in early intervention services. These populations include the poor, Hispanic and migrant people, American Indians, and military personnel assigned to Washington. We will discuss what appear to be common and uncommon cultural features as well as similarities and dissimilarities of the service systems developed by or for them.

What issues are posed to and by families considered to be poor?

Because of our focus on public birth to three services, we were led to interview parents and agency personnel associated only with public services -- health, welfare, and education. Most people reliant on certain public services have to qualify based on low or no income. In effect, we interviewed among populations and services within a larger environment of poverty.

> This is a poor county so everybody is poor. People are low income, have high risk pregnancies, and can't get medical care. When you add ethnicity to this, the kids are at more risk for everything, including being mis-identified on an early intervention screening due to language differences and different behavioral norms.

In service resources-poor counties or portions of counties where Hispanics and American Indians constitute the largest segment of the population, key informants suggest that families within the smaller White population are encountering comparable problems in accessing services, based largely on the common attribute of poverty. These families often share some of the linguistic barriers of their ethnic and racial counterparts. They also have a large number of agencies coming in to "fix their lives." While some are fairly transient, they lack the support of migrant services; those who are settled lack the support of reservation-based services.

Some characteristics often associated with poverty are:

- a high degree of geographic and seasonal mobility
- lack of trust in agencies
- lack of investment by agencies in these communities
- inability to speak the language of agency personnel
- inability to bridge differences in values and perceptions.

The Problem of Geographic and Seasonal Mobility

As noted elsewhere in this report, families with children with disabilities or special health care needs require extensive supports—extended family, friends, employers, physician, neighborhood, community, school, church, and human services. However, the working poor tend to move often, in search of work, and thus lack direct attachment to these supports at the point where their child is perceived as having some difficulty.

Families migrating within or between these areas do not have the benefit of prior community attachments and knowledge necessary to support them and their child when the child is diagnosed. It is not safe to assume that in-migrating families (whether ethnic or military) are connected to their culture **at the local level**. Much depends on how they are connected, to whom, and how knowledgeable and skilled that part of the culture is about services. If their cultural contact is knowledgeable, someone (e.g., friend, migrant services, tribal health) can help bridge them to community-based services, particularly those services "where you go if you have no money".

Even military families in-migrating with clear diagnoses and treatment plans have to immediately conduct research within the base and the local community; some families are so overwhelmed at this point that they are unable to help themselves. Often, basic needs (e.g., obtaining food, employment, and housing) precede whether their child is immediately entered into birth to three services.

Attachment, for constantly mobile families, is a temporary state. Seasonal employment poses a problem, for example, for migrant workers, even those served by migrant services. As they move seasonally from community to community and county to county, based on employment, continuous attachment, transfer, records exchange, and tracking become major problems in providing services to their children.

American Indian families who live on reservations may experience fewer of these problems associated with mobility. However, many American Indian families move from community to community inside and outside of Washington, in pursuit of schooling, employment, and other family purposes and then experience the same loss or fragmentation of attachment.

In some of the state's resource-based industries, the issue is less seasonality and its resulting in intermittent qualification for services than low to moderate wages and no employer-based insurance. Under this scenario, the family's ability to pay for what is needed for their children with disabilities is very limited. Eventually, the children do receive services, but only after the family economic situation has declined to a much lower point. At that point, the ebb and flow of employment and unemployment puts them above and below the qualifying income limits. Each time they drop below the qualifying limit, they may have to re-apply for public benefits, such as SSI, a tremendous amount of paperwork.

> People can be deterred from service by its sheer volume or failing to fill it out properly, it's going to come right back to you and you can wait another six months for service.

The Lack of Trust in Agencies

Many of the families who consider themselves poor feel disconnected to the institutional service world; they often operate with a different sense of time and urgency. They feel at an immediate disadvantage in entering service buildings and offices that feel like department stores. They feel isolated and that they do not belong.

Parents and agency personnel pointed out that there was great distrust of agencies.

> They distrust systems. When you mingle extreme and widespread poverty as we have here (with 93% of our kids on the free lunch program) with cultural privacy, they seem to have so many agencies in their lives that the prospect of working with one more agency, having one more person in their home, having to interact with one more agency, is unacceptable, even unthinkable. It's simply more trouble than it's worth. Especially when your overriding concern is with putting food on the table, finding housing, finding transportation, keeping your older kids in school, keeping your husband at home. In the hierarchy of interests, the infant may not be the priority if the other priorities in your life are in crisis.

Key informants suggest that the differences between agency and family are based on neither race/ethnicity nor poverty, but on a combination of the two appearing differently in different counties.

The Lack of Investment by Providers in the Poor

Some public agency informants suggested a ubiquitous lack of investment in or even a bias against the poor among some medical and dental providers.

For example, they suggest that while some of the bias by providers against the class of families paying with medical or dental coupons is based in fact, that they often miss scheduled appointments (creating an unfilled gap in the provider's schedule), they also suggest that providers are not sensitive to the fact that the same people who rely on medical or dental coupons also have major transportation difficulties, due to simple economics and the limitations of public transportation in many of these areas. They often will not recognize or tolerate the fact that medical appointments may be a lower immediate priority than other matters. Since it takes some effort to find solutions to these problems, such as calling to verify appointments, some physicians and dentists find it easier simply to limit or eliminate this class of client family.

Bias by providers also appears as

- an intolerance of the behaviors and/or appearance of some clients in their waiting rooms or treatment rooms
- an intolerance of the lack of feedback from the parents, who listen to what they are told and then leave, without reassuring the provider that they have heard, understood, and will comply
- an intolerance of parents with a different, culturally-determined way of communicating about these matters with strangers and authority figures.

Inability to Speak the Language of Agency Personnel

There are linguistic barriers for poor families just as there are for families from other cultures. Poor families and the agencies often do not speak the same language. Thus, for the poor and for ethnic communities, the lack of sympathetic mutual translation is a basic barrier. For example,

> the issue is less whether there is a Spanish-speaking provider, but the degree to which that provider is culturally-competent, and has been trained to listen, to not judge, to not intrude. It is not just the words.

In many situations, neither party manages to provide cultural or linguistic translators for the interaction. For example, it was startling to find, in counties with very large Hispanic populations, long-term providers who neither speak Spanish nor employ persons who speak Spanish. Some key informants attribute this problem to prejudice, whether it is bias against the impoverished, against racial or ethnic groups, or against the non-English speaking. Some suggest that the bias against poverty in their area is a coded expression against race.

The ability to communicate in English is not equivalent to communicating cross-culturally. For example, many informants note that the idiom and style of speech of many American Indian people are often mis-read by local service professionals as ignorance or impairment. As they move away from on-reservation services, provided by other American Indian personnel or providers more experienced in American Indian cultures, the likelihood of communication problems with local community providers increases markedly. However, some key informants suggested that the farther these American Indian clients travelled from local community services, the less likely they were to encounter certain racial, ethnic, and linguistic biases.

Inability to Bridge Differences in Values and Perceptions

With years of experience in serving cultural communities, some agency informants commented how surprised they were with the number of unserved children there were in need of services in these communities.

> We know they're out there, but we don't know who they are. Some cultures are more protective of their youngsters and will just not bring their children to screenings or services.

Poor, ethnic, and racial communities reportedly differ from one another in their attitudes

- towards their children
- towards "appropriate" service
- towards agency help or involvement and
- towards the notions of disability and special health care needs.

Some communities and populations are suggested to be more accepting and "reality-based", looking at their child as "this is the way that it is," leading to a rejection of possible interventions but some avoidance of the distress and loss attributed by other cultures to child disability and delay. Agency personnel are often frustrated and even horrified by this expression of acceptance of the situation, the rejection of help, and lack of a visible grieving process, all culture-bound phenomena.

Within these "non-reporting" cultures and populations, referrals tend to come through persons, such as secretaries and para-professional aides, who are from the cultural communities and act as intermediaries. Such referrals proceed slowly through careful inquiry and exploration and generally indirect means, leading to an invitation to a developmental screening. These seem more effective than general or community-wide screenings, which seem more useful to parents who are simply seeking validation of their child's normal development.

The following discussions highlight some characteristics of early intervention services for three large and special populations in the seven counties in which we interviewed—Hispanic migrants, American Indians, and enlisted military families.

What issues are posed to and by Hispanic migrant populations?

Many Washington counties have large and growing populations of Hispanic families. These populations are not as homogeneous as it might appear on the surface. Some families have settled in these counties and communities for decades. Others are more recently settled. Still others make their primary residence in one county but migrate seasonally to other counties for employment. Some are routinely migrant from other states and return to Washington counties and communities on a regular basis; others migrate once but never return. Some migrate from other countries in Central and South America and lack American citizenship and even green cards. Some come as entire families, but many come as only portions of families, such as uncles, brothers, and nephews together.

Economics

Many Hispanic residents in some counties live in a never-never land of economics. Some are working in the lowest paid employment categories and are paid under the table, show no income, pay no income taxes, receive no insurance benefits, and so qualify for poverty-based programs. Thus, seasonality of income does not affect their qualifications for benefits. However, many lack green cards which prevents them from obtaining services. Only some programs are open to children who are not "legal;" other programs are only open to those who are legal residents.

One migrant agency respondent noted that many private practitioners will not accept medical coupons or Hispanic children.

> They will tell you this right out when you're trying to set up an appointment. It's not a racial thing, but an economic thing, I believe. It's also very difficult for our kids. We send a lot of our kids to the Farmworkers' Clinic and they provide a lot of services. However, a lot of time, they're booked solid. The Medicaid reimbursement rate does not seem to be a problem for **them**; they don't reject on that basis.

Cultural Differences in the Evaluations of Children's' Development

For some purposes, each of these groups and clusters operates as a distinct culture, requiring agencies to have an appropriate response if the children and families in need are to be served.

Some birth to three services providers are frustrated by the developmental differences ascribed to ethnic cultures. For example, one IFRC noted how difficult it was to assess Hispanic children because they developed walking at a later age ("they are not left to crawl around, they are always carried around") and speech ("they are not as vocal, they speak when spoken to").

> We could assess all of those Hispanic kids and probably get them into services because they aren't fitting into the dominant culture. But that's not fair. Yet, when they get to kindergarten, they are going have to measure up.

However, Hispanic parents, both mothers and fathers, are reported to be actively engaged in and compliant with their children's treatment programs.

Parent Supports

Within ethnic cultures, informal networks often operate differently from networks in other communities. For example, parent-to-parent groups operate with different organization and rules within different cultural settings. The migrant parent-to-parent network is reported to be extremely effective and close knit. Given the cultural norms about privacy and sharing, even parent support groups within these cultures operate differently from their more general counterparts. Within these cultural groups, many large extended families and friends live together or in proximity, due to both custom and poverty, creating different networks and supports within the community.

Health Practices

Different cultures also may contain different health care practices. For example, in some Hispanic communities, there are lay or unlicensed (in the U.S.) traditional health providers who are generally consulted by women prior to accessing any public system, including the pre-natal providers. These providers do therapeutic touch, spiritual healing, herbs, HIV-AIDS education, and even injections and blood-drawing. Many obstetricians in the communities are reportedly unaware of the ubiquity of these providers. However, in one county, one birth to three case manager is developing a working relationship with such providers in order to have them refer to the birth and share information.

Migrant Services

Birth to three services to migrant children are coordinated through the Migrant Council. The Council provides some services and refers families to others. Because of the nature of the funding of the Migrant Council, its personnel appear to have more discretion over their budget and thus appear less constrained than some other services; in effect, they appear somewhat less categorical, much like the Children with Special Health Care Needs (CSHCN) program.

The Migrant Council, like some rural community approaches, tends to maximize its non-agency resources, by turning to the community and by making sure that community agencies are operating together at maximum efficiency and coordination. The smaller the human community, the more resourceful agency people seem to be in finding resources to match the needs.

Some key informants suggest that the settled Hispanic poor families have a more difficult time than do the migrants because there are fewer special services focused on them; Migrant Council services can do much less for them and Farmworkers Clinic serves only some of them. Being "settled" is a limiting factor, requiring families to rely mainly on generic state services.

Making Contact

In the most rural areas within the interviewed counties, most sparsely populated and with American Indian and Hispanic residents, the referrals to birth to three services staff, particularly developmental pre-school, come from different parts of the community. Friends, school aides, health aides, relatives, and others all tell professional staff that they should visit particular homes.

> Somebody will tell you that there is a family down the road that needs some service. For confidentiality and readiness purposes, we provide information to the person doing the referral; they contact the family. Since some of the families don't read, we convey the information to the referrer and hope they convey enough of it accurately so that parents will contact us.

> Some people either call or visit me at home; I don't know how they find me. Sometimes the father may not be ready to accept what is going on and mothers need to talk to me privately. It's difficult to establish eligibility without the father's knowledge.

> Since 10% of migrant Headstart enrollments are reserved for children with disabilities, we know we have quota slots available; it would be too easy to fill these slots with other kids without this requirement. We make a fairly heavy recruitment effort to identify and enroll these children.

While some key informants suggested that the unseen unserved are not numerous within the Hispanic migrant population, those who are unserved are in "drastic" need of services. Their families have come to work and put food on the table; having to make appointments and have interviews with multiple agency personnel just does not fit into their life schedule.

> That means we have to go to them and to their homes. We find out about them because our families work so closely together as do our program staff.
>
> Even though migrant parents want what is best for their child, sometimes it just does not happen. And it is worse if I am an illegal alien. It's going to be very hard for you to come into my home or anything.

Advertisement in ethnic communities takes a variety of forms.

> We do door-to-door survey and recruitment. It can be dangerous work, since the majority of our staff is female and the work must be done in the evening. We have had no major incidents, but it can be very scary. We also do public service announcements, flyers, everything.

Key informants who felt positive toward home-based contact and service delivery express some concern about the safety of these services.

> We have homes out there that are unsafe for female staff and home visitors to go into. We have alcohol and drug abuse. We have angry dads who don't want us in their homes. We don't let them go out unless they take their cellular phones. If I were to start up an outreach program, I wouldn't do it in homes but in community centers or churches or youth centers.

Initial engagement of migrant families can be very difficult.

> As a matter of cultural diversity, we have migrant families who, for whatever reason, are simply not ready to enter the world of mainstream medicine. They want to take other steps prior to modern medicine. Once they're in service and know what it can do for them, we have little difficulty keeping them in service.

Some Hispanic cultures fear an agency's lack of understanding of their culture. Many Hispanic residents and migrants continue to hold very traditional cultural beliefs. Many will not allow access to medical records from birth onward.

> How can you come and tell me these bad things about my child? You don't know the way we live or the way we are. So what you're asking may be impossible.

Initial rapport is critical with these families.

> If, in that initial contact, you cannot build rapport and trust, you're not going to get in the door again. If you're not of that culture, if you're Anglo, professional, highly educated, well-dressed, you're not going to be very successful with those families, even to be able to make an assessment. What's best is if you're a male, bi-lingual Hispanic person. You make a mistake if you talk to the mother, you have to talk to the head of household—the father or the oldest male. It is like dating...before you get to date the girl, you have to meet with, be tested by, and get the permission of the father. He is usually at work during the typical workday, which makes permissions and scheduling very difficult. The mother, in order to help the child, may go around the father, but that will only cause more problems.

Accessing Services

In terms of screening and assessing Hispanic children for services, agency personnel suggested that "culture-directed" agencies (e.g., Migrant Council, Farmworkers Clinic) were not as restrictive as public schools.

> In schools, who must typically and traditionally test and qualify children is the school psychologist, white, educated, and well-dressed. It is rare to find a Hispanic school psychologist assigned to pre-school. In addition, school home visitors seldom want to work for pre-school special education, so we can't substitute one person for another.

Migrant families are often embarrassed or ashamed at having strangers in their homes; they may have 20 people living there or have no heat, phones, or furniture. Agencies may have to make appointments by letter or knock on doors uninvited.

> From the bottom of the pyramid of service, for parents looking up at it, it looks like an awful lot of people coming in to work with my child, asking me a lot of questions, a lot of paperwork, a lot of waiting to find out if I qualify for this or that, and how am I going to pay for all the things my child needs. The basic qualification is American citizenship and that is the biggest problem; the rest of the families qualify for most services based on their low income. The paperwork for parents with kids in Migrant Headstart is small, but once they are referred for other services, that's when the headaches start.

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Every migrant center has a paid full-time parent involvement advocate. That is the person the parent is likely to contact first, rather than a professional or clerical staff member.

> These para-professional advocates are mostly persons who have worked through the system themselves, so they are familiar with the needed sensitivities and organizational skills. At the very least, they are intended to make the parents comfortable enough to come in and seek services.

These "community people" are considered critical to successful engagement of these children and their parents in birth to three services. People want to see people who look and sound largely like "community people" to serve their families. Who constitutes "community people" differs from Hispanic culture to culture.

> They are more equipped to meet different needs than are the professional staff, based on their experience and cultural sensitivity and respect for and understanding of the beliefs of families. They provide the process needed in each situation confronted by parents, rather than only the form. They get the families to outcomes. They help the parents to approach and get through some gates. The professionals help the parents through the closed gates when the advocates fail. Our voice is usually big enough to get them through, based on our history of close cooperation with agencies throughout the county and state. That carries a lot of weight at the service delivery level on a case-by-case basis. It doesn't hold true for the county ICC, an environment where some fighting goes on.

Finding provider staff who are sensitive to families' attachment to traditional medicine is a big challenge for both educational and health agencies. As one agency planner noted,

> Most who are willing simply don't know how.

Since the migrant Hispanic population is made up of very different national backgrounds sharing a common language, poverty, and migrancy,

> we have to work closely with each family and child to bridge real differences. Each family is its own culture, more than just its national culture. Some of our staff are Spanish-speaking mono-lingual and we learn a great deal from them, how people think about things differently.

Often the first and only referral the migrant center has to make is to the county's birth to three services network,

> with whom we work very closely. They will take care of other referrals from there. If it is with someone else, we will help schedule their first appointment and provide transportation. If they tell us they need some translation, we may accompany them.

When the migrant center encounters a school district lacking birth to three or development services,

> We have to fill in for them, via contracts with individual practitioners in speech, consultants, and so on. It's a very big and expensive problem, given travel times and small budgets. We have tried hard to convince school districts to provide these services, but they refuse. Our other problem is that they would not want to provide these services over the summer when the schools are closing and our kids are just coming in for harvest, from April to September. Getting independent contractors in for the summer is difficult as well.

Maintaining Contact

Agency personnel note that, if the provider intends to provide family-centered services and provide education in parenting, one cannot use the beautiful, full-color, text-replete publications provided for this purpose with most Hispanic and American Indian families.

> If you want to truly empower these families, you have to rely on materials in or common in that home, no matter how poor.

It is very hard for many migrants (persons who stay in an area for less than one year) to access and take advantage of a system of birth to three services because they are in the local service area for such short periods of time. This requires the Migrant Council services system to follow them and provide services in each of the areas in which they reside and work on a temporary basis.

> Many of our families are returning families, so they know where to come to look for comprehensive migrant services.

What issues are posed to and by American Indians?

Indian/County Relationships

Counties have very different and complex histories in providing services to American Indian residents, both on-reservation and off-reservation. They also have complex histories with tribal governments. In the counties where we interviewed, these relationships have been characterized as being somewhere among "improving", "strained", and "hostile".

Until relatively recently in some counties interviewed, there has not been much engagement by local authorities of tribal authorities: birth to three services. Reportedly, agency personnel were not accepted into tribal communities and tribal agency personnel were adamant that agency personnel not interfere in the lives of tribal members. Much of this is attributed to the personalities of the public agency persons involved, not the institutions per se.

> Some insist on going in and telling our people what to do. That works with some people who are really needy, but doesn't work at all with competent people.

Some tribes also object to state agencies coming into their communities and conducting needs assessments, with no resulting outcomes in terms of consequent services. Some difficulty is explained by the geographic distances between community and tribal services, reducing the amount of communication and mutual knowledge. These problems have to be overcome at the person-to-person level as well as the formal inter-agency and government-to-government levels. Agencies of both forms of government note the need to apply the time and energy to set up meetings where information and needs can be shared.

While these relationships may be strained, there are still referrals to public service agencies from the American Indian communities. These tend to result less from tribal than from public health/CSHCN nursing, WIC nursing, at-risk nursing referrals, and local First Steps perinatal projects. Other than the CPS-initiated referrals, most of these referrals result from initial hospital referrals to the county public health nurses as well as home visits by public health nurses. Screenings appear to be done in a variety of home and clinic locales -- WIC visits, PHN visits, CPS visits, tribal clinic, and IHS facility.

The participation of tribal human service workers in publicly-funded programs varies by location, worker, and even client. Given complex political and family relationships in and around reservations, who is involved in service may depend less on specific medical conditions and agency missions than other, often invisible and unspoken factors.

Public agency personnel suggest that, until trust is built with American Indian families over time, many parents tend to provide only minimal information about their children. They contrast this reticence with other families who "run on endlessly" about their children. Much more is shared when and if a personal relationship has been established. In the interim, much more information is gleaned informally from community persons who are not immediate family members. In birth to three services, as in other areas, most local agencies and the tribes agree that continued mutual suspicion and rejection can and must be overcome by mutual inclusion among tribes, community agencies, and providers.

Family Perceptions and Values

Non-Indian public agency personnel suggest that American Indian families and communities are much more accepting of their special needs children than are other families and communities. They suggest that this may result in fewer services for some borderline children and less agency involvement in these families' lives, but much more emotional and psychological support for the parents. Later, these children may "float" through school without active intervention, the result of lower expectations by parents and/or teachers; the latter is of questionable legitimacy. As one DDD caseworker put it,

> I know that a lot of them who should be on my caseload are not.

Some American Indian informants report that some parents on reservations are frustrated by their community's lack of knowledge and insight into the special needs of their children, since these children will grow up in this community. They suggest that the community is almost too accepting of these children, without seeing their actual limitations and what they will mean in the future.

> When they can't win a race, they give them a prize anyway. Lower expectations can be as damaging to the child as the real negative stuff.

In some American Indian communities, there are far fewer male than female heads of household. It is reported that single young mothers often lack some basic communication skills and social skills and are often afraid their children will be removed by a public agency, based on the recent history or memory of Indian child welfare removal and involuntary boarding school removals and experiences.

Given these conditions, most reservation-resident parents who

> all of a sudden perceive some failure in their child would be struck with total confusion as to what to do and where to go. That would hold them back from looking for help for some period of time. Some would be fearful of the small town politics when people find out; some fear that they may be blamed for the disability, as they see FAS (Fetal Alcohol Syndrome) moms blamed.

These parents would most likely start their search with the WIC program, where they have the direct experience of the most support.

> The WIC lady is from this community and she knows about us and the school district. The other place they might turn is the IHS health clinic, where people have more negative feelings. The IHS clinic is not very specialized but they are good about referrals outside the reservation. In many emergency situations, people would go directly outside, bypassing the clinic entirely.

Reservation residents express concern about allowing outsiders to intrude in their lives. They exercise the power to choose when they will come in and report something and ask for help.

Parent Supports

Unlike some other communities, American Indians do not appear to create new social inventions, like Parent-to-Parent groups, to replace what, in the past, may have been provided by family, neighborhood, and community. The existing family, clan, and other structures appear to continue undisturbed by children with special needs.

Even family members do not intrude into the lives of these children and parents, unless there is abuse or neglect. There is a view expressed that

> the very young children belong to the parents, until they become three or four where they become more like public property.

Managed Care in American Indian Communities

Depending on tribal governmental policy, American Indian people resident in different counties receive health and social services from the Indian Health Service (IHS) and their tribal government. Under PL 638, tribes choose which services they will provide to their own members and which remain with the IHS. Presently, different tribes are in different stages of the development of their own selected array of human services. Tribes and American Indian non-profit agencies can also contract with state agencies for the provision of state-funded services to their own members and others. American Indian people can receive public services provided to all other Washington residents.

Depending on the length of time that different tribes have been engaged in the provision of health and human services and the wealth of the tribe, each tribe provides a different array of services. In many instances, the array of services for small children is greatly underdeveloped, according to key informants.

In some remote tribal communities, there is a lack of daycare and preschool adapted to the children under three. They lack both facilities and personnel. In some areas, the special education teachers from the local school district come to the reservation facilities to provide services; the teachers are reportedly running themselves ragged and the children are still underserved, since the tribal clinics do not offer a full range of services.

Some reservation residents see their tribal social services program as a service for older people,

> not for kids, not a place where you would go for birth to three issues. They tend to take their kids to the school district.

In more than one county, there was reported to be little interaction among IHS health clinic, tribal social services, the school district, and the IFRC on infants and toddlers. Key informants expressed concern that gatekeepers to services were not skilled in the use of basic assessment tools. Given the needs of these children, many are sent to the urban centers in or outside the county.

Tribal services were suggested to be protective and possessive of their members and less familiar with community-based services and resources available to them off-reservation, so the children lack access to local available services. It is suggested that this gap is likely to be bridged as tribes seek and obtain contracts with agencies for the provision of medical, dental, and IFRC services and as tribal services establish face-to-face ongoing relationships with non-tribal community-based services. It is also suggested that different kinds of approaches to services may be required to get American Indian children and families identified, recruited into service, and served.

What issues are posed to and by Military Families?

In-migration of Military Families Requiring Services

Washington is home to a number of major national defense facilities, housing large numbers of personnel and dependents. Under normal circumstances, this would result in a number of new families in-migrating to Washington with normal rates of disabilities and special health care needs. In their reliance on civilian support services in each county, the number of such children and families would be easy to project.

However, national military health care policy has dictated that families with children with such conditions are arriving in larger than expected rates. Defense budget cuts have emphasized the need to do as much in-house as possible, cut the number of services and providers, closed some medical centers and consolidated certain services into three national sites, and requires that the military hospitals pay for some non-military community-base health services out of their own budget.

A major military hospital in one of the counties we visited has been designated as one of only three national military sites housing the Exceptional Family Members Program (EFMP). For the best use of military medical resources, families containing an exceptional member are or can be relocated to one of these three sites in order to access needed services. Military personnel can request compassionate reassignment for this purpose, although in many instances the family is relocated but the military member of that family may be stationed elsewhere.

These EFMP sites are reported by many to be making strides in understanding the manifold problems of these families and in seeking collective solutions with the civilian services in the affected counties. This long-term task is particularly important as many families live, in fact, off-post and in the county and the military medical centers lack many of the resources required by these parents. They either lack the required specialty service or the service is oversubscribed, resulting in significant waiting lists for service.

As military downsizing and economizing continues, it is likely that increasing numbers of such families will be relocated to these centers, may outstrip the capacity of the military medical centers, and increase the demand on the local county birth to three services.

The Problems of Military Families

The world of military parents of disabled and special health care needs children is a complex subset of Washington parents in general. It was not possible, in the short time available to this inquiry, to draw a complete picture of the strengths and weaknesses of the military-local civilian system serving these families. However, it is key for some counties, because of the concentrated presence of these military families and their demand for local civilian services.

Military parents suggest that they are the victims of great misperceptions by local civilian human services provider agencies. The popular view of the military enterprise as providing total socialized care results in parents being constantly asked, "Isn't the military taking care of its own?" One state agency caseworker reportedly told a sergeant's wife,

> I am tired of military people dumping their kids on the state.

This perception and attitude is particularly galling to military personnel who have been Washington residents for many years and have long-term residence in established community neighborhoods. They also note that civilian services seem quite unaware that these parents are experiencing greater co-pay requirements and higher deductibles within the military services for dependents, resulting in rapid erosion of family financial resources.

> The co-payment is 20%, not bad when the bill is $50, but horrible when the bill is $30,000.

Interviews with these military personnel and their dependents indicate clearly that, as parents of children with disabilities or special health care needs, they have become increasingly poor. Those whose incomes are not below 180% of the federal poverty level find themselves only marginally above that level.

Military parents suggest that their financial problems are eased somewhat when the enlisted member's unit is deployed overseas. Apparently, increased allotments, reduced numbers of persons living in the household, and separate checking accounts result in some additional funds flowing into the family while making the stateside single parent more eligible for some civilian services. However, offsetting this economic gain is the loss of one parent from central roles of parent and spouse; this, it is suggested, results in family breakup.

Military parents also noted a series of significant Internal Revenue Service recalculations of income, such as the uniform allowance, which resulted in higher calculations of family income, though no tangible increase in real income, but threatened eligibility for income-based public services. One respondent suggested that the calculation of military income now includes a wide array of services that were not previously calculated, even though they are not discretionary and have no family income implications. As a consequence of the new calculation, a number of poor military families have reduced access to such supports as medical coupons and SSI. Both officers and enlisted personnel are threatened by promotion; as their income goes up, their income-based services become capped.

Military parents suggest the need to have a very independent spouse, under the best of circumstances. As these personnel are deployed elsewhere, leaving their families behind, the spouses "will take the brunt of it." Effectively single parents with 24 hour a day responsibilities for the disabled or special needs child, who have the greatest need for respite care or child day care, have great difficulty in getting it. One officer noted,

> we're qualified for respite but we don't have it. We haven't found the right brick to bring that wall down.

Military parents appear to feel very fortunate to be in Washington state, where they have access to what they consider to be great, if often difficult to access and coordinate, medical resources and the range of services available in their county. One father noted that, regardless of the many problems, the military parents are not negative, merely frustrated, worried, and stressed.

One issue confronted by military families is the disagreement among military and civilian providers and military and civilians payers as to who is to be the first payer for each service. The debates seem to go on forever and parents feel that they are bouncing between state and military payers, back and forth, back and forth.

Living with Managed Care in Military Facilities

As with other managed care systems, the military medical centers desire to provide all of the **medical** services required by their constituents; **family** services are a much different matter. When the medical service is unavailable or insufficient, there is some natural reluctance by the system to admit the weakness and pay for community-based services.

However, at some point and often with great parental prodding, the military system must consider waiving its requirements and authorizing the payment of funds to civilian services. Naturally, given the limited resources, this is done reluctantly and can require a number of separate gates and gatekeepers to achieve. Military parents report that it can take 60 days to obtain the required waivers, resulting in long periods of non-service for their children. One parent reported that it took four years for his daughter to be categorized as long-term disabled. "The bottom line," he suggests, "is that the child suffers."

Such medical centers, because they are short-staffed in various clinics, end up with long waiting lists for services, "so it seems to backlog everything," including authorization and referral to civilian services. The hospitals will handle emergencies, but if non-emergency services, such as evaluation, can be deferred for weeks or months, the hospitals will tolerate that. Post-evaluation services may simply place a child on one or more clinics' waiting lists.

The situation in Washington is reportedly getting better, in response to parental concerns and Specialized Training of Military Parents (STOMP) advocacy. However, some military parents feel that these attempts at improvement in early intervention are neither sincere nor yet effective, since, at the gatekeeper level, the messages are still

- no waivers
- take what we give you
- wait on the waiting list
- no triage based on severity or significance
- first-come, first-served.

As one sergeant noted,

> EMFP does not mean that you will get served, only that you are in the program.

Parent Support

Only somewhat offsetting the costs to these parents is the community that is formed by the military unit, as supplemented by on-post neighbors who provide immediate support. Off-post residency results in somewhat less community and neighborhood support. In all cases, however, the low incidence of children with these conditions separates these families from their more "normal" counterparts and limits the nature of the support the others can provide. For these reasons, community-based IFRCs and parent-to-parent supports become more critical.

Military parents report the great value of local parent-to-parent groups and IFRCs. One father noted that "civilians help us through the military maze." As a result, some IFRCs suggest that they are viewed as a threat by some military gatekeepers.

Contrasting Migrant, American Indian, and Military Services

Unlike the Washington population at large, and the poor in particular, migrants, American Indians, and the military have unique human service systems specific to each. From the perspective of some outsiders, these systems are to provide for most, if not all, of the needs of these unique populations.

Conversely, one cannot infer the provision of services from the mere presence of services. For example, while it might seem that military hospitals would provide extensive birth to three services to military dependents and IHS/tribal health services would do the same for American Indian constituents, according to key informants, this does not seem to be the case:

Military

- the military provides primarily medical and mental health services, not the full range of required services
- the military provides few pediatricians, so most physicians are not aware of infant and toddler developmental signs and diagnostic procedures
- while many enlisted personnel are Medicaid-eligible and could rely on a broader array of community-based services, there remains the question of who is to pay for military dependents in civilian services. To be paid by the military (a managed-care system), such services require a letter of "nonavailability of services" which is often difficult to get when diagnosis is uncertain. This all results in delays, being on waiting lists, compelling parents to either wait for services or to try to pay for them out-of-pocket.

Indian Health Services

- IHS is a managed-care system, reportedly offering sometimes inconsistent medical performance and limited experience in the specialized needs of infants and toddlers with disabilities and special health care needs.

Tribal Human Services

- some tribal services are unfamiliar with community-based services for these infants and toddlers, even in the urban areas, so the children lack access to available services, based on lack of referral.

Migrant Council

- migrant services seem much more resourceful, due to many more years of struggling to obtain services
- migrant services tend to use state, county, and private providers to the maximum, since their principal role is screening, diagnosis, and referral.

Conclusion

While our discussions with informants about these populations was often quite detailed, we readily acknowledge that each is worthy of separate and more thorough inquiry. In effect, we believe that these discussions raised as many questions as they addressed.

We cannot overstate the significance of the cultural differences between and among these populations and between these populations and the general population of Washington. These cultural differences profoundly affect the way in which people perceive their children, perceive and address agencies, communicate with one another and with agencies, and take actions in behalf of their values. These differences also affect the way in which agency personnel perceive and explain these populations and take or do not take actions in their behalf.

The cultural differences and experiential similarities with services between and among these populations is more complex than we can delineate here. Ethnicity alone is unlikely to explain these differences and similarities among ethnic cultures. We believe that they are explained by a great interaction among ethnicity, poverty, mobility, and ruralness. Similarly, the differences and similarities among the military and other working poor are explained by the interactions between poverty and mobility.

Note: Our discussion of different populations is based on more detailed findings included in the "Source Document" available upon request from the Office of Research and Data Analysis.

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Purposes

This research exploration into barriers to services, underservice, and unservice was intended to confirm, reject, clarify, or re-state commonly-held assumptions and perceptions about barriers to service, underservice, and unservice. Its conclusions or depictions are bounded by issues of nongeneralizabilty. Its principal goal is identification and definition of key elements worthy of future prevalence study.

This exploration was able to expand upon and refine some of the qualitative findings of the preceding Department of Health surveys and focus group efforts. These inquiries provided some general organizing concepts in the area of unresolved problems in the services environment. For example, they discovered different problems in each stage of a family's relationship to services -- finding out, getting in, getting what is needed, and fitting in. They highlighted certain issues, such as transportation and eligibility, as key impediments to care. However, their inquiry was limited to those families who were, in fact, actively receiving services. Among these families, inquiry was conducted only among those who self-selected to participate.

This research exploration intended to focus more on the ubiquity and content of those family, community, and agency elements and processes which result in barriers, unservice, and underservice. What we anticipated emerging from this exploration (and which did, indeed, emerge) was a theory which depicts the character of gates which must be passed in order to get service. It also explains certain family, community, population, and agency characteristics which complicate the perception and passage of gates.

This study, unlike the Department of Health studies, was focussed on four locales or counties in order to link family, community, and agency characteristics and processes into individual county explanations of barriers, unservice, and underservice. Given the complexity of these counties and the service ties among counties, it was not possible to either completely explain these four counties or limit interviews to these counties. Interviews were actually conducted in three additional counties contiguous to the original four.

Field Methods

The exploration required direct face-to-face contact with the parents of infants and toddlers experiencing delaying or disabling conditions as well as key informant interviews with community-based service providers and coordinators.

Counties

Early intervention services are understood and organized by county or groups of counties. In order to have access to the widest possible array of elements and processes, we required data sources which contain widely differing characteristics. The characteristics sought to be represented were suggested in previous studies and background discussions with experts in provider agencies and advocacy organizations —urban, rural, border county, multicultural, migrants, military, American Indian, well-integrated services, and less integrated services. In addition, due to budget restrictions, it was determined desirable to seek counties which field workers could access easily by automobile. The selected counties represented these characteristics.

Public early intervention services, while organized by counties, rely on larger service linkages to adjacent and non-adjacent counties and even states. As a result, some interviews were held with private agency and parent respondents in three additional counties and one state adjacent to the counties which were the subject of this study.

Due to the exploratory purpose of this research and its sampling approach, it is unknown to what degree findings are generalizable to other counties; however, our purpose was not generalizability **per se**, but the discovery of the key factors for future surveys to calculate generalizability in other locales.

Key Informants

Parents, agency and community informants were drawn strategically rather than randomly. They were not necessarily representative of all children, parents, or providers within their county. They were chosen to reflect different views and/or experiences.

Agency and community informants were identified in the following way. We originally identified those in "positions to observe" and explained the elements and interactions regarding families and services in these locales. By "position to observe", we mean persons who are differently located within the range of agencies and community organizations involved with these families, who act as advocates or intermediaries between the agencies and families, and who are members of families considered unserved or underserved. In effect, we saw our pool of potential informants as differently positioned in this community and agency world and, as a consequence of being differently positioned, having different opportunity to observe that world and draw conclusions from their observations. Comparing these observations and conclusions within the same locale would provide the key common and uncommon elements for future quantified inquiry.

The parent informants were a "snowball" sample. Some parents were introduced to us initially by our agency and community informants. These parents in turn suggested other parents for interviewing who had similar or different experiences.

By constantly comparing observations and explanations within counties, we identified some key elements functioning as barriers or potentially resulting in unservice. Initially, we had intended to cease interviewing in a locale when 1) each core category of inquiry was saturated with complete and unvarying data, depictions, or explanations and 2) we had searched and received all types of dissimilar, deviant, contrary, or negative observations and explanations. We particularly sought out contrary voices and cases because these perspectives may be either more accurate representations of an actual reality than the agreed-upon reality (culture) of the larger association or contain elements which shed new light on these realities. We were able to accomplish this fairly well with agency and community informants. However, given the discovered complexity and diversity of the experiences of parent informants, the fieldwork among parents ceased when we had exhausted the time available.

Within this period, however, we were able to interview a satisfactory array of informants in each county. We selected within classes of persons in the location-bounded universe of persons involved in these agencies and organizations; the selection of classes and persons was based on the function each class and person serves for the research itself -- that is, parents, IFRCs, DD case workers, special education teachers, public health nurses, ICC members, child agency supervisors, tribal workers, advocates, and others.

The interviews were conducted among comparable sets of informants in the four counties. By an analytic process of triangulation, we created a picture of the objective and subjective, actual and perceived conditions leading to barriers to service, underservice, and unservice in these counties.

Using "snowball" sampling (i.e., having key informants direct us to other informants), the research project approached key informants in the provider/parent-to-parent world to help identify, make contact with the served, underserved, and unserved families, obtain informed consent, and facilitate a discussion of absolute or relative unservice. This was found useful in bridging the gaps between field researchers and family and community cultures, and reduce the perceived threat of the engagement.

We believe the sample obtained provides high validity, but largely unknown generalizability. The criteria for selection were those of theoretical purpose and relevance, not of geographical or organizational circumstance. Since data analysis occurred concurrently with data collection, as we discovered additional classes of issues, we expanded the pool of persons to include those in a position to observe and explain those issues.

While, theoretically, service gaps are easy to identify by inventorying all services and all eligible children (attached to their service needs) by geographic locale, this identification did not resolve the issues of service beyond mere availability and proximity, such as accessibility and equity. IFRCs and local service providers provided detailed and measurable analytic categories and relationships, specific to their locale. Primary referrers were the best source of information on the dynamics of attachment failure between family and provider agency.

However, while we had ease in contacting and interviewing individual parents and groups of parents, we had great difficulty contacting the seen and unseen unserved families directly through these techniques. We had little luck in the same way that direct service providers and community intermediaries had difficulty in establishing contact with these families. From others, we learned bits and pieces of their stories; from experiences of other families which had passed through some gates with difficulty, we could cautiously extrapolate the failed experiences of others at these and similar gates. We discovered a great deal about some failed passages through extensive discussions with front-line community persons, providers, and advocates about their observations and explanations. These are reported in this study's source document, "Birth to Three Early Intervention Study: Enrollment of Children with Disabilities and Special Health Care Needs in Washington State Public Programs".

Parents as Respondents

In the process of identifying and interviewing parents, we focussed on parents of children who were receiving a variety of publicly funded services co-ordinated by the Birth to Six State Planning Project. Consequently we missed all those not in service at the time:

- the unseen unserved
- those suspected of needing service but never served
- those who had dropped out of services
- those parents who had:
  - given up
  - abandoned their children and families
  - had their children removed by child protective services
  - given up their children for adoption
  - entered and exited services with successful or sufficient outcomes, however these are defined.

Missed also were those receiving all services elsewhere:

- parents of children receiving all services from private and privately paid sources
- parents of children receiving all services from migrant, military, or American Indian providers.

Given the focus on the coordination of variety of services, we tended to miss the perceived minority parents of children experiencing:

- only mild to moderate or reversible conditions for whom the existing array and organization of services is meeting either their needs or their level of expectations
- behavioral or emotional conditions only
- a label of "at-risk" due to environment or other circumstances.

We tried to capture the diversity of experiences of special populations. However we may have missed

- parents to whom we were not introduced due to difficulties of language, culture, geography, or lack of required intermediary.

Since we focussed on parent's experiences we missed the first-hand accounts of :

- siblings
- extended members of the child's family.

The parents we met and interviewed appear to represent the survivors, those who, under the most stressful conditions, were still keeping their spirits intact and their heads above the water. The children of these parents were experiencing one or more serious or severe disabilities or special health care needs. The parents were experiencing stresses and losses in a number of areas of personal, marital, and family life. They were described to us as constituting the majority of families enrolled in service.

We interviewed both married and single parents including those who were divorced, separated or abandoned. The intact marriages appeared, while very stressed, to be very sound to begin with. Informants suggested that flawed spousal relationships could not withstand the overwhelming stress placed on the family by a child with severe disability.

Parents expressed themselves with a great deal of energy and heat. While a sign of voice, empowerment, and engagement, it also seemed to cost them a great deal. They literally exploded with the events, conditions, and feelings of their lives. When asked about this, they pointed out to us that few, if any, persons in the services delivery system had ever asked them about the barriers to service they had experienced.

Parents reported that after telling their stories to the agency and the agency noting that they were due these services, they were informed there was insufficient funding for them to receive the services. Parents said agency personnel seemed to be asking for parent sympathy rather than the reverse. One IFRC reported accompanying a young couple to a panel meeting with an agency which offered a service they needed. They were given a description of the services, and only then the news that there was no money. In our interviews, parents clearly desired to be speaking through us to the policymakers. Many parents viewed the interview as an opportunity for hope. Hope rather than despair or anger pervades this service area, hope that policymakers will hear and sympathize with them.

Since we interviewed parents referred to us by other parents or by agencies, we were concerned that a singularly biased viewpoint would emerge. What we found, however, was corroboration throughout a network of what parents had told us, since agency staff, providers, advocates, friends, and others shared parts of their stories. Indeed, IFRCs generally agree that about 90% of what their client parents tell them they have been told by or they themselves have experienced with service agency staff and providers.

Some of our respondents occupied twin roles -- parent of a disabled child and agency person responsible for services (e.g., IFRC, teacher, nurse, pediatrician). Sometimes their responses to questions varied by whether they viewed the question as related to their role as parent or as agency/program representative. Often their responses from both vantage points were the same.

We did not attempt to verify respondents' perceptions and explanations with observation of actual behavior nor with "official" documents or data. We tried to accurately capture and recast their perceived reality as it was given to us.

Convergence and Divergence of Perspectives among Parents and Agency Informants

We did not find decidedly different versions of reality when interviewing providers, IFRCs, and parents. Most front-line agency workers, regardless of agency or professional discipline, echo and support parental concerns about the "system." However, we did find very different emphases on what was important and unimportant as well as different estimations of how sufficient the system was in meeting the needs, among and between parents and agency representatives.

What distinguishes perceptions is not merely people viewing the world from different points of view, but seeing different orders of magnitude. What you see really depends on what **level** you are operating within and what significance, values, timeframe, and foreground you see at that level.

It is interesting that, in some counties, there is accord between and among parents and agency personnel about the basic features, strengths, and weaknesses of the local birth to three services, whereas in other counties there is serious discord, based on discrepant views of what is needed, what is provided, and how well it is provided. These counties posed a great difficulty for us, as we could only record the discrepancy, but not document or explain it.

Foreground and Background Differences

Many providers focused entirely on issues in their foreground such as concrete visible improvements at the local level: for example, school district programs, outreach and childfind activities, multidisciplinary teams, IFRCs, parent-to-parent groups and activities, and local innovations in quality improvement. To other providers, focussed on larger issues of health, these local level improvements, while very helpful to **some** individual families and collective coordination, were not seen to offset the major system obstacles to **all** families. Many providers seemed preoccupied with their inter-agency relations and internal management issues. Some providers seemed to be looking at our issues of barriers, unservice, and underservice for the first time, as if these issues lay outside their ordinary concerns. Some seemed unable to differentiate birth to three children from all other children in service.

Barriers

Parents understood our questions about barriers, impediments, gates, and gatekeepers far more readily than did many direct providers. Often, when providers spoke about barriers, they focused more on the gatekeeper than the system within which the gatekeeper operates.

For example, IFRCs suggested that there are some wonderful people in these service institutions, but that they are a very small percentage of the whole; they also said that some providers are good for some kinds of families and poor for others. It appears to be a question of proper match between parent attributes and gatekeeper/provider attributes. This accounts, in their minds, for the relief that their families express once they have found and attached themselves to a good gatekeeper. Many providers seek no explanation beyond this "person-based" theory of gates.

Analytic Method and Explanations

In focusing on these issues, we as exploratory researchers must deal with matters of explanations, perceptions, conditions, situations, actions, interactions, and patterns, beyond or underlying "person-based" theories of action.

While our interviews were guided by a structured interview guide, data analysis occurred concurrently with data collection. The data derived from field interviews directed the analysis and the analysis identified new data collection avenues pursued in subsequent interviews.

The initial analytic categories were derived from a review of extant Washington agency reports and from discussions with agency informants. These categories were further refined through secondary analysis of the primary sources underlying these reports. Preliminary discussions with involved state agency personnel and community-based providers and advocates provided a wealth of insights and opinions on the subjects of barriers, underservice, and unservice at the local level where families live and seek services.

The product of these discussions was a range of topics and explanations, based on the depth of experience and the social or agency location of these persons in birth to three services. The range of topics appear in lists below. The explanations seemed well-grounded, but the emphases differed widely; well-informed and insightful people differed in their explanations of reality. These differences were repeated in the fieldwork within the counties.

All perspectives and formulations by all informants were considered legitimate. Our task was to break these statements down into their basic elements and then recast them into an observational and recording screen—gates. This resulted in the complexity appearing in the body of the report and its source document as well as the functional performance areas discussed with agency and community informants, including:

Early Contacts with Children and Families

- child find outreach
- accessing cultural communities
- accessing more geographically remote areas of counties
- early identification
- screening
- multidisciplinary assessment
- physician involvement in assessment
- inter-agency case planning
- medical referrals to support groups and social services
- medical referrals to specialists
- case management

Agency Coordination

- plan implementation and plan coordination
- inter-agency communications about individual children
- inter-agency coordination of services to children
- inter-agency cost-sharing
- cross-cultural communications
- providing integrated array of needed services for children
- best fit for child compared to fitting child into available services
- inter-provider communications about individual children
- IFRC caseloads
- agency caseloads

Services and Supports

- services to children with mild to moderate impairments/delays
- home-based care
- quantity of respite care
- quality of respite care
- provider commitment to children with special needs
- family empowerment in care planning
- advocacy for client child/families
- "family-oriented" services
- supportive services to families (e.g., counseling education)
- Parent-to-Parent support groups
- cultural support groups/organizations
- transportation services
- referrals to services outside of the local service area
- local innovations and solutions.

Problems discussed with agency and community informants included:

Fairness

- fairness in diagnosis
- fairness in treatment

System Limitations

- lack of alternative services
- complex and multiple funding eligibility criteria
- getting funding for required services
- legal barriers to service
- lack of specialized screening skills
- lack of appropriate diagnostic equipment
- limited number of service spaces available for children/families
- waiting lists for services—formal, informal
- waiting lists for public funds

Unserved and Underserved

- unscreened children
- getting medical referrals to specialists
- family characteristics
- parents as the principal advocates for their children
- agency beliefs and values about these children/families
- agency bureaucratic maze
- geographically dispersed services
- provider unwillingness to accept referrals
- number of medically fragile children
- children with poor nutrition
- lack of relevancy of services with clients' cultural values
- homeless families
- substance-affected families
- inappropriate and increasing use of emergency rooms.

Limitations on Generalization

As already mentioned, we did not begin our inquiry with this large list of concerns, but ended up with this list as respondents raised their issues in response to our questions. It must be noted that we did not ask our respondents for a balanced and politic view of their local service realities. Since we were interested primarily in barriers to services, underservice, and unservice, we did not ask them about all that was "right" with their local services, but what was "wrong." We focused more on problems than solutions; although many parents and agency personnel with extended system experience offered realistic system-level solutions.

In field work, it is easiest to get **explanations**, since actors can easily state their perceptions of their situation and rationales for their situated behavior. However, we attempted to record not only what people **said** their views were, but what they actually said they **did** to alter the real-life experiences of children and families. Talking which does not result in action is likely to be interesting only because of this feature.

The field research relied on individuals' statements of their perceptions and actions on their own terms -- what did they perceive, what did they want to do, what did they do, did they accomplish what they hoped to accomplish, and what helped or prevented them from accomplishment? In describing the conditions, situations, words, and actions of these persons, we compared and could explain more accurately why they fully or partially succeeded or failed.

Combining these perspectives produced a complex picture of elements and forces interacting to result in barriers to service. The picture, which appears as the substance of this report, is the researchers' construction of the minimum explanation of the relationships among the elements, but not the magnitude or prevalence of these elements in these or other locales or in special populations statewide.

Given the exploratory nature of this study, we are not in a position to talk about magnitude or prevalence of the service problems and underlying conditions. Our respondents and counties are not considered atypical, but we still cannot generalize from our respondents to other uninterviewed parents, providers and agencies in these counties or in other Washington counties. This must remain the subject of a future study using the results of our exploratory findings and sampling techniques suited to accurately estimate magnitudes and prevalences.

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